

Community Health Worker–Reported Observations of Physical and Mental Disabilities among Children in Rural Setting in Rwanda

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Abstract

Background:

Physical and mental disabilities in childhood affect growth, development, and social participation, particularly in rural, low-resource settings where access to early diagnosis, care, and support systems is limited. Globally, 10–11% of children aged 0–17 years live with moderate-to-severe disabilities, more than half of whom reside in Sub-Saharan Africa and South Asia. In Rwanda, reported prevalence remains low, suggesting potential under-identification. Community Health Workers (CHWs) play a key role in identifying children with disabilities and facilitating referral to care. However, their capacity to identify physical and mental disabilities remains poorly understood. This study describes CHW-reported observations of childhood disabilities and examines factors associated with these observations.

Methods:

We conducted a quantitative study using secondary data from 358 CHWs. CHWs reported whether they had observed at least one child with a physical or mental disability (yes/no) in their communities. Descriptive statistics summarized CHW characteristics and reported observations. Bivariate and multivariable logistic regression analyses were used to examine factors associated with CHWs' observation of childhood disabilities.

Results:

Among 358 CHWs (median age 45 years; 57.7% female), 63.6% reported observing at least one child with a disability. Frequently reported physical disabilities included genu valgum (38.3%), clubfoot (36.1%), and hearing impairment (34.0%). Commonly reported mental disabilities included developmental delay (40.1%) and epilepsy (21.7%). Most CHWs (94.6%) reported referring cases to health facilities. Female CHWs were more likely to report observations than males (OR = 2.02, 95% CI: 1.2–3.2, $p = 0.003$), as were CHWs with 11–15 years of experience (OR = 2.2, 95% CI: 1.0–4.5, $p = 0.03$).

Conclusion:

CHWs play a critical role in community-based identification and referral of children with disabilities. Gender and experience influence observation patterns. Strengthening CHW capacity through targeted training, screening tools, and improved referral systems may enhance early identification and equitable access to care in rural settings.

1. Background

Disabilities, whether physical or mental, remain a significant public health concern, particularly among children in rural settings¹. Globally, between 10% and 11% of children aged 0–17 years, approximately 280 million individuals, live with moderate-to-severe disabilities. More than half of these children live in Sub-Saharan Africa and South Asia².

Despite evidence that early identification and intervention improve long-term developmental and social outcomes for children, identification of childhood disabilities remains challenging in low-resource settings³. Evidence indicates that mental health disabilities such as developmental disorders are particularly under-recognized in low-resource settings due to limited awareness and diagnostic capacity^{4,5}. Physical disabilities such as mobility, visual, or hearing impairments are more observable. However children living with such disabilities still face challenges in timely identification and management⁶.

In Rwanda, the 2019–2020 Demographic and Health Survey estimated a 5.9% prevalence of physical and mental disabilities among children aged five years and older, and a 2.2% prevalence among children aged 10–14 years⁷. These figures likely underestimate the true burden, as the World Report on Disability suggests a global prevalence of disabilities of around 15%⁸.

Rwanda's 2014 school census recorded 24,862 children with disabilities across preschool, primary, and lower secondary schools, representing only 0.5% of children under 17 years and 0.85% of enrolled students, implying that many children with disabilities either do not attend school or were not identified as having a disability during the census⁹.

Community Health Workers (CHWs) are central to Rwanda's primary healthcare system and serve as the first point of contact for most rural families, delivering preventive and basic curative services and improving access to care in underserved areas¹⁰. Given their close engagement with households, CHWs have the potential to play a critical role in identifying children living with physical and mental disabilities at the community level¹¹. Nonetheless, both physical and mental childhood disabilities often remain hidden and underreported, especially in rural communities¹². CHWs have the potential to bridge this gap; however, their ability to recognize, manage, and refer children with disabilities can be limited by training gaps, inadequate diagnostic tools, and the complex nature of disability detection in children¹³.

Global evidence underscores the importance of community-based approaches in disability detection¹⁴. Previous studies indicate that CHWs may recognize physical disabilities but struggle to identify mental or developmental conditions due to insufficient training, awareness and persistent stigma¹⁵. Nonetheless, CHWs' position as the first point of contact in rural communities makes them key informants for understanding and quantifying childhood disabilities.

Burera District, in Rwanda's Northern Province, remains predominantly rural and faces challenges related to limited healthcare infrastructure and a scarcity of skilled healthcare professionals¹⁶. CHWs play a

crucial role in addressing these gaps by linking households to care¹⁷. However, little is known about how CHWs detect and manage childhood disabilities in this context¹⁸.

This study aims to describe community health worker reported observations of physical and mental disabilities among children aged 0–18 years in Burera District, and to explore factors associated with CHWs having observed children living with disabilities. We expect the findings to provide practical insights to strengthen CHW training, improve early detection, and inform inclusive child health strategies in rural Rwanda.

2. Methods

2.1 Study Design and setting

We employed a cross-sectional design, using a survey distributed to CHWs in Burera district. Detailed methodological procedures for the survey design and implementation have been published elsewhere¹⁹. We summarize the key elements relevant to this study below.

We conducted this study in Burera District, a predominantly rural area in Rwanda's Northern Province, located along the border with Uganda, approximately 96 kilometers (about 59.65 miles) from Kigali, the capital city. The district has mountainous terrain and is served by one hospital, Butaro Level Two Teaching Hospital, and 19 health centers. According to the 5th population housing census, Burera district has a population of 387,729²⁰. Among them, 54,046 were children under the age of five, as reported by the Health Management Information System (HMIS)^{21,22}. The most recent census counted 12,347 people living with disabilities aged five years and above in the district. We selected this district due to its rural nature, limited access to healthcare and disability support services, and the crucial role of CHWs in healthcare provision.

2.2 Study population and Sampling

The study population comprised CHWs, who serve as frontline healthcare providers delivering basic health services at the community level and linking communities to the formal health system. Due to their close and continuous engagement with households, CHWs are well positioned to report on disability types and rehabilitation needs at the primary healthcare level.

We used a two-stage cluster random sampling strategy. In the first stage, we listed all 19-health centers in Burera District and randomly selected 10 health centers using a computer-generated random number list, considering each health center as a cluster. The ten randomly selected health centers were Butaro, Rwerere, Gahunga, Rugarama, Cyanika, Gitare, Ndongozi, Kinyababa, Rusasa, and Kirambo.

In the second stage, we obtained lists of villages within the selected health centers from local leaders. We identified 358 villages served by 1,432 CHWs (four per village). We assigned each CHW a unique

identification number and drew a proportionate sample from each health center using a random number generator. To avoid duplication within villages, we randomly selected one CHW per village to participate.

We included CHWs who had worked in their role for at least one year in Burera District to ensure adequate familiarity with community health needs, and we excluded those with less than one year of experience.

2.3 Data Collection and Measures

Data were collected from Community Health Workers (CHWs) as part of a previously published parent study (Dukuzimana et al., 2025). A structured questionnaire was used to obtain information on CHWs' sociodemographic characteristics, professional experience, and their observations related to identifying and managing physical and mental disabilities among children in their communities.

The questionnaire was developed for the parent study and informed by existing tools, including the World Health Organization Systematic Assessment of Rehabilitation Situation (STARS) framework and related rehabilitation assessment instruments. It was adapted for use in this study to capture CHWs' observations of childhood disabilities. CHWs reported whether they had observed at least one child with a specific type of disability using binary (yes/no) responses.

The questionnaire was administered through face-to-face interviews conducted by trained data collectors using the REDCap (Research Electronic Data Capture) system, a secure web-based platform for research data collection and management. Responses were entered directly into the system during the interviews.

Prior to the main data collection, the questionnaire was pilot tested among a small group of CHWs in a comparable rural setting. Feedback from the pilot testing was used to refine question clarity, ensure contextual relevance, and improve consistency in interpretation across respondents. Data quality was further ensured through comprehensive training of data collectors, real-time data entry checks, and field supervision.

The English version of the questionnaire is provided as a supplementary file (see Additional file 1).

2.4 Statistical Analysis

We cleaned the data from 358 CHWs prior to analysis to ensure completeness and accuracy. There were no substantial missing data for key variables included in the analysis; therefore, complete case analysis was performed. We used descriptive statistics, including frequencies and percentages for categorical variables, and medians with interquartile ranges for continuous variables, to summarize participants' sociodemographic characteristics and their reported observations of physical and mental disabilities.

To explore relationships between key variables and the observation of children with disabilities, we conducted bivariate analyses using Chi-square and Fisher's exact tests, applying Fisher's test when expected cell counts were less than five. We then performed logistic regression to identify factors

associated with disability observation and included variables with p-values < 0.2 from the bivariate analysis in the multivariate model. We set statistical significance at $\alpha = 0.05$. We managed and analyzed the data using Stata version 15 (StataCorp, College Station, TX, USA).

2.5 Ethical Considerations

The Institutional Review Board of the University of Global Health Equity, Rwanda, approved the primary study (Ref: UGHE-IRB/2024/328, dated 11 June 2024). Butaro Level Two Teaching Hospital and participating health centers granted additional permissions. We conducted the present analysis using secondary data from this approved study. This secondary analysis used de-identified data, and no additional participant contact or data collection was conducted.

3. Results

3.1 Characteristics of study participants

Our sample included 358 CHWs from Burera District. The majority of participants were aged over 40 years (67.5%), with a median age of 45 years (IQR 37–51). Most participants were female (57.7%) and married (96.4%), and the majority (73.9%) had a primary education background. Regarding professional experience, almost all CHWs (96%) had 5–10 years of experience in their roles, with a median working experience of 11 years (IQR 5–16).

The socio-demographic characteristics of CHWs are presented in Table 1.

Table 1
Socio-demographic characteristics of study participants.

Variable	Frequency (n)	Percentage (%)
Age (years)		
< 30	22	6.6
30–40	86	25.9
> 40	224	67.5
Sex		
Male	140	42.3
Female	191	57.7
Level of Education		
Primary	241	72.6
High School	90	27.1
Vocational Training	1	0.3
Marital Status		
Single	3	0.9
Married	320	96.4
Divorced	2	0.6
Widowed	7	2.1
CHWs' Working Experience		
< 5	71	21.39
5–10	89	26.8
11–15	75	22.59
> 15	97	29.22
No. of households being served		
< 50	215	64.7
50–100	104	31.4
> 100	13	3.9
Note: Values are presented as frequencies (n) and percentages (%). Percentages may not sum to 100 due to rounding. All variables describe the sociodemographic and professional characteristics of Community Health Workers (CHWs) included in the study.		

Variable	Frequency (n)	Percentage (%)
Age (years)		
Abbreviations: CHW = Community Health Worker; n = number; % = percentage.		

3.2 CHW-reported identification of childhood disabilities

211 CHWs (63.6%) reported observing at least one child living with a physical and mental disability in the communities they served. Among physical disabilities, CHWs most commonly reported genu valgum (38.3%), clubfeet (36.1%), and hearing impairment (34.0%), followed by vision impairment (22.9%), and cerebral palsy (20.2%). For mental disabilities, CHWs most commonly reported observing at least one child with developmental delay (40.1%), followed by epilepsy (21.7%).

CHWs reported that they most commonly referred children with disabilities to health centers (94.6%). They rarely reported providing onsite treatment (0.3%), other forms of management (0.6%), or taking no action (1.5%). Table 2 below details the observations reported by CHWs.

Table 2

Proportion of CHWs reporting observation of at least one child with physical or mental disabilities, by disability type and management practices

Variable	Frequency (n)	Percentage (%)
Overall CHWs observations of Physical and Mental disabilities		
CHW's reporting an observation of at least one child living with a disability	211	63.55
Physical disabilities		
Genou Valgum Cases	127	38.25
Club Feet Cases	120	36.14
Hearing Impairment Cases	113	34.04
Vision Impairment Cases	76	22.89
Cerebral Palsy Cases	67	20.18
Mental disabilities		
Developmental Delay Cases	133	40.06
Epilepsy Cases	72	21.69
Reported actions related to disabilities identified at the community level		
	314	94.6
Referred to health center	1	0.3
Onsite treatment	2	0.6
Other management	5	1.5
No action was taken		
Note: Values are presented as frequencies (n) and percentages (%). Percentages represent the proportion of CHWs reporting observation of at least one child with the specified disability or management practice. Multiple responses were possible, as CHWs could report more than one type of disability or action. Abbreviations: CHW = Community Health Worker; n = number; % = percentage.		

3.3 Factors Associated with Identification

In the bivariate analysis, sex was significantly associated with CHW's self-reported observation of disabilities in children. Female CHWs were more likely than males to identify children with disabilities ($p = 0.001$).

No significant associations were found with age ($p = 0.559$), marital status ($p = 0.960$), level of education ($p = 0.649$), or years of working experience ($p = 0.127$). Factors associated with CHWs' observation of

childhood disabilities are presented in Table 3.

Table 3

Bivariate Analysis of the factors associated with CHW's Observation of Children with Disabilities.

Sociodemographic variables	Categories (If Applicable)	CHW's Observation of Children with Disabilities		P Value (Fisher's)	Pearson Chi 2
		Yes	No		
Age	< 30	12(5.69)	9(7.44)	0.581	0.559
	30–40	59(27.96)	28(23.14)		
	> 40	140(66.35)	84(69.42)		
Sex	Male	55(45.45)	66(54.55)	0.001	0.001
	Female	136(64.76)	74(35.24)		
Marital Status	Single	2(0.95)	1(0.83)	0.940	0.960
	Married	204(96.68)	116(95.87)		
	Divorced	1(0.47)	1(0.83)		
	Widower	4(1.90)	3(2.48)		
Level of Education	Primary	155(73.46)	86(71.07)	0.752	0.649
	High School	55(26.07)	35(28.93)		
	Vocation Training	1(0.47)	0(0.00)		
Tailored Job Training	Yes	197(93.36)	117(96.69)	0.313	0.197
	No	14(6.64)	4(3.31)		
CHWs working experience (years)	< 5	39(18.48)	32(26.45)	0.128	0.127
	5–10	53(25.12)	36(29.75)		
	11–15	54(25.59)	21(17.36)		
	> 15	65(30.81)	32(26.45)		
Households responsible to serve	< 50	138(65.40)	77(63.64)	0.418	0.413
	50–100	67(31.75)	37(30.58)		
	> 100	6(2.84)	7(5.79)		

Note: We present values as frequencies (n) and percentages (%). “Yes” and “No” indicate whether community health workers (CHWs) reported observing children with disabilities in their assigned communities. We calculated p-values using Pearson's chi-square test or Fisher's exact test, as appropriate, and considered p-values < 0.05 statistically significant.

Abbreviations: CHW = Community Health Worker; n = number; % = percentage

In the multivariate analysis, female CHWs were significantly more likely to observe children with disabilities compared to male CHWs (AOR = 2.02, 95% CI: 1.2–3.2, $p = 0.003$). Similarly, CHWs with 11–15 years of experience had higher odds of reporting an observation of at least one child living with a disability (OR = 2.2, 95% CI: 1.0–4.5, $p = 0.030$). Multivariable logistic regression results are shown in Table 4.

TABLE 4: Factors associated with CHW's Observation of Children with Disabilities.

Variables		Crude Modes			Adjusted		
		Odds Ratio	95% CI	P-Value	Odds ratio	95% CI	P-Value
Sex							
	Male	1.1	[1.3,3.4]	0.499			
	Female	2.2	[0.8,2.5]	0.001	2.02	[1.2-3.2]	0.003
Training done since joining the role of CHW							
	Yes	2.0	[0.6,6.4]	0.2	0.7	[0.7-1.3]	0.3
	No	1.6	[1.3,2.1]	0.00	2.4	[0.7-7.9]	0.14
CHWs working experience (years)							
	5-10	1.2	[0.6,2.2]	0.5	1.2	[0.6-2.4]	0.46
	11-15	2.1	[1,4.1]	0.03	2.21.7	[1-4.5]	0.030
	>15	1.6	[0.8,3.1]	0.4	1.5	[0.8-3.3]	0.10

Abbreviations: CHW = Community Health Worker; COR = crude odds ratio; AOR = adjusted odds ratio; CI = confidence interval; Ref = reference category.

4. Discussion

Our study explored CHWs' self-reported observations and practices related to identifying and managing childhood disabilities in Burera District, Rwanda. Overall, 63.6% of CHWs reported observing at least one

child with a physical or mental disability, suggesting a substantial community-level burden.

CHWs most frequently reported observing conditions such as developmental delays, genu valgum, clubfoot, and hearing impairment. These conditions are primarily visible or functional impairments, which aligns with findings from other low- and middle-income countries (LMICs), where CHWs tend to identify physical disabilities more readily than less visible neurological or mental health disorders²⁴. This difference may stem from the nature of community-based work: observable physical limitations are easier to recognize during routine household visits, whereas conditions such as cerebral palsy or epilepsy often require clinical assessment or longer-term observation to be accurately identified²⁵.

We found significant sociodemographic differences in detection patterns. Female CHWs were twice as likely to report observing children with disabilities compared to male CHWs (OR = 2.02; 95% CI: 1.2–3.2; $p = 0.003$). One possible explanation for this finding is that female health workers may have closer relationships with mothers and children, which could facilitate the disclosure of health concerns and improve case identification²⁶. In rural Rwandan settings, gender norms frequently assign women greater responsibility for home visits and caregiving activities, potentially providing female CHWs with increased access to households and more frequent interactions with caregivers²⁷. This enhanced access and trust within caregiving environments may increase their opportunities to observe and identify children with disabilities compared to their male counterparts.

Our findings are also consistent with qualitative evidence from Uganda and Tanzania showing that gendered roles give female CHWs greater access to households and closer relationships with caregivers, facilitating disclosure and case detection²⁸. However, evidence from larger quantitative reviews suggests that the influence of CHW gender is context-dependent, with heterogeneous effects across settings. This suggests that while gender may play a role in shaping CHW effectiveness, it does not operate uniformly across contexts but appears particularly relevant in rural settings such as Burera District in Rwanda, where social norms influence caregiving roles and access to households²⁹.

Experience was another significant predictor, as CHWs with 11–15 years of service had higher odds of reporting disability observations (AOR = 2.17; 95% CI: 1.0–4.5; $p = 0.03$). One possible explanation is that accumulated field experience enhances CHWs' ability to recognize subtle signs of developmental delays, physical impairments, and typical mobility patterns, particularly in community-based settings where access to diagnostic tools is limited³⁰. Over time, repeated exposure to diverse cases and ongoing interaction with families may improve CHWs' observational skills, confidence, and decision-making in identifying children who may require further assessment or referral. Additionally, more experienced CHWs may have stronger relationships within their communities, increasing trust and the likelihood that caregivers share concerns about their children's health and development.

In contrast, formal education level was not significantly associated with improved detection of childhood disabilities. In this study, formal education refers to general schooling attained prior to joining the CHW role, rather than job-specific or clinical training. This finding may indicate that practical, experience-based

knowledge and gender are more influential than formal educational attainment in enabling CHWs to identify children with disabilities, particularly in low-resource, community-based contexts.

Similar findings have been reported in studies from Western Kenya, where educational attainment alone did not significantly improve CHW performance, and contextual factors such as community support, supervision, and resource availability played more critical roles^{28,29,31}. These findings highlight the importance of experience-based learning and suggest that strengthening practical skills, supervision, and community engagement may be more effective than relying solely on educational background to improve detection of childhood disabilities.

Although most CHWs reported referring children with disabilities to health centers, very few reported providing onsite management or alternative forms of care³². These findings should be interpreted cautiously, as they are based on self-reported practices and do not confirm whether referred children successfully accessed or received appropriate care. Evidence from other low- and middle-income country (LMIC) settings suggests that referral completion is often limited due to barriers such as distance to facilities, transportation costs, stigma, and limited availability of specialized services. These constraints may contribute to gaps between identification and effective care, particularly for children requiring rehabilitation or long-term support. In this context, even where community-based health insurance schemes exist, indirect costs and health system limitations may continue to hinder access to services, underscoring the need to strengthen referral systems and follow-up mechanisms.

Overall, our findings show that CHWs are well positioned to support early detection and referral of children living with physical and developmental disabilities at the community level. However, differences in experience and gender appear to influence CHWs self-reported observations.

Implications for Policy and Practice

This study highlights the role of CHWs as a potential key point of contact for identifying children living with disabilities in rural communities. Strengthening their capacity through training, structured screening tools, and support mechanisms may enhance early detection, although training alone was not significantly associated with improved outcomes in this study.

While this study did not directly assess access to rehabilitation services, the observed gap between CHW referral and reported management practices suggests that barriers beyond detection may limit access to care. These may include challenges related to service availability, referral system coordination, and indirect costs, highlighting the need to strengthen linkages between community-level identification and facility-based care.

Recommendations and Future Research

Future research should further examine factors influencing CHWs' ability to identify children living with disabilities in community settings. Strengthening referral systems, including feedback mechanisms

between health facilities and CHWs, and ensuring accessible rehabilitation services will be essential to bridge the gap between detection and care. Policymakers should also consider expanding rehabilitation coverage in rural areas and supporting CHWs through targeted supervision and community-based follow-up strategies.

Researchers should conduct future studies for better understand the factors that influence CHWs' ability to identify children with disabilities in community settings. In particular, further studies should explore how different types of training, supervision, and practical experience contribute to CHWs' detection capacity.

Longitudinal or mixed-methods studies could provide deeper insight into how CHWs' experience over time influences their ability to identify and refer to children with disabilities. Additionally, future studies may assess the effectiveness of specific interventions, such as structured screening tools or targeted training approaches, in improving early identification and referral outcomes.

Future research should also focus on estimating the true burden of childhood physical and mental disabilities in rural Rwanda, as this study relied on CHW-reported observations rather than confirmed case counts. In addition, further investigation is needed to assess the appropriateness and outcomes of referrals made by CHWs, including whether children reached health facilities and received adequate care. Understanding these pathways will be critical to strengthening the effectiveness of community-based identification and referral systems.

Study Limitations

This study has several limitations. First, CHWs assessed childhood disabilities based on their observations rather than direct clinical evaluation or caregiver self-report. In addition, we asked CHWs to report disability observations using a binary (yes/no) measure, which does not capture the number of children affected and therefore does not allow estimation of prevalence. As a result, the findings reflect CHWs' reporting and observational practices rather than the true burden of childhood disabilities in the population.

However, third-party (proxy) reporting has been widely used in large-scale population surveys, including UNICEF-supported instruments such as the Washington Group Child Functioning Module³³, and it provides valuable insights into patterns of case identification within primary healthcare systems.

Furthermore, it is unclear to what extent CHWs used standardized tools or criteria when identifying disabilities, as reporting may have relied on individual judgment. This may have introduced variability in how disabilities were recognized and reported across participants.

Second, the cross-sectional design limits our ability to draw causal inferences; therefore, we interpret observed associations as correlational rather than causal. Third, we did not capture potentially relevant factors such as CHWs' level of supervision, detailed training content, or access to referral systems, which may influence their ability to identify and report disabilities.

While most CHWs reported referring children with disabilities to health centers, this study did not assess the appropriateness or outcomes of these referrals. Therefore, we should interpret these findings as reflecting CHWs' reporting practices rather than the effectiveness of referral processes.

Finally, we conducted this study in a single rural district in Rwanda, which may limit the generalizability of the findings to other settings.

Conclusion

CHWs play an important role in the community-based identification and referral of children living with physical and developmental disabilities in rural Rwanda. In this study, CHWs' self-reported observation of children with disabilities was associated with gender and years of experience, highlighting the potential role of practical experience in recognizing childhood disabilities.

Overall, the results suggest that CHWs can contribute effectively to the early identification of childhood disabilities in community settings. Further studies are needed to improve our understanding of the factors that influence referral processes and access to services following identification.

Declarations

Ethics approval

The Institutional Review Board (IRB) of the University of Global Health Equity (UGHE) in Rwanda granted ethical clearance for this study (Ref: UGHE-IRB/2024/328 dated 11th June 2024). The study adhered to the ethical principles outlined in the Declaration of Helsinki. The researchers obtained written and signed informed consent from all participants.

Consent to participate

Not Applicable.

Availability of data and materials

The data that support the findings of this study are derived from a secondary dataset collected under the project "Rehabilitation needs at rural primary health care settings" in Burera District, Rwanda. These data are not publicly available due to data use agreements and institutional restrictions but may be made available from the corresponding author upon reasonable request and with permission from the data-owning institution.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

MU and DU conceived and designed the study, conducted the data analysis and drafted the manuscript. PNM, MJD, and EN contributed to data collection and study implementation. MU, DU, PNM, MJD, MAF, and EN contributed to data interpretation and critically revised the manuscript for important intellectual content. All authors reviewed and approved the final manuscript and agreed to be accountable for all aspects of the work.

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