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Time to care and factors influencing appropriate Sudan virus disease care among case patients in Uganda, September to November 2022

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ABSTRACT

Objectives: Early isolation and care for Ebola disease patients at Ebola Treatment Units (ETU) curb outbreak spread. We evaluated time to ETU entry and associated factors during the 2022 Sudan virus disease (SVD) outbreak in Uganda.

Methods: We included persons with RT-PCR-confirmed SVD with onset September 20–November 30, 2022. We categorized days from symptom onset to ETU entry (“delays”) as short (≤ 2), moderate (3–5), and long (≥ 6); the latter two were “delayed isolation.” We categorized symptom onset timing as “earlier” or “later,” using October 15 as a cut-off. We assessed demographics, symptom onset timing, and awareness of contact status as predictors for delayed isolation. We explored reasons for early vs late isolation using key informant interviews.

Results: Among 118 case-patients, 25 (21%) had short, 43 (36%) moderate, and 50 (43%) long delays. Seventy-five (64%) had symptom onset later in the outbreak. Earlier symptom onset increased risk of delayed isolation (crude risk ratio = 1.8, 95% confidence interval (1.2–2.8)). Awareness of contact status and SVD symptoms, and belief that early treatment-seeking was lifesaving facilitated early care-seeking. Patients with long delays reported fear of ETUs and lack of transport as contributors.

Conclusion: Delayed isolation was common early in the outbreak. Strong contact tracing and community engagement could expedite presentation to ETUs.

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Introduction

Both the case-fatality and the transmission of Ebola disease (EBOD) can be reduced with early isolation of and appropriate care and treatment for EBOD patients at Ebola treatment units (ETUs)

Abbreviations: cRR, crude risk ratio; EBOD, Ebola disease; ETU, Ebola treatment unit; SVD, Sudan virus disease.

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[1]. This requires active case finding, monitoring of contacts, and rapid isolation of contacts who become ill [2,3], as well as strong health-seeking behavior of persons with EBOD symptoms [2,4]. As such, communities must be aware of EBOD-related symptoms, both the early nonspecific symptoms as well as the late EBOD-related symptoms. Given that early EBOD-related symptoms are nonspecific, knowledge of being a contact of an EBOD case is crucial for early care seeking by the communities [5–7].

In many African communities, ill persons first seek care in the informal health sector, such as from traditional healers, drug shops, or informal nurses [8,9]. This can delay reaching appropriate care

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and effective isolation in an ETU, facilitating the spread of infection. During EBOD outbreaks, informal care-seeking has been attributed to mistrust of the government, the perception that formal health facilities were too overwhelmed to respond effectively to EBOD, and long distances to public health facilities [10,11].

During September 2022 to January 2023, 142 confirmed cases of Sudan virus disease (SVD) were recorded in Uganda [12]. Throughout the outbreak, the delays in isolation of SVD case-patients at ETUs and the influencing factors were not well understood. We explored these issues during the 2022 outbreak in Uganda to better understand time to isolation and inform future targeted response efforts.

Methods

Study design

We collected both quantitative and qualitative data. The outcome of this study was time to effective isolation, defined as isolation at the ETUs, where patients with pending test results waited while receiving supportive care. We included data for all patients from the nine affected districts in Uganda that had SVD cases after the outbreak was declared (September 20–November 30, 2022) (Figure 1). We chose this time period because before September 20, there were no functioning ETUs and therefore SVD case-patients could not have had effective isolation.

The first ETU was opened on September 20 at Mubende Regional Referral Hospital. Two additional ETUs were opened during the 2022 EBOD outbreak: one on September 30 at Madudu Health Centre III in Mubende District and another on October 15 at Entebbe Regional Referral Hospital in Kampala District. To reduce spread of infections, from October 15 to December 17, the government of Uganda instituted a lockdown in Mubende and Kassanda Districts, the two districts at the epicenter of the outbreak [13,14].

Data sources and study variables

We abstracted data from the line list for RT-PCR-confirmed SVD case-patients on demographics, survival status, number of health-

care points visited, date of symptom onset, date of effective isolation, and whether or not the SVD case-patient was listed as a contact of another case-patient before symptom onset (“known contacts”). We characterized the timing of symptom onset as “earlier” (from September 20 to October 15, 2022) or “later” (from October 16 to November 30, 2022). We calculated delays from patient symptom onset to effective isolation and categorized it as short (within 2 days of onset), moderate (3–5 days), and long (≥ 6 days); the latter two were considered “delayed isolation.”

We evaluated delays and the number of health facilities visited by SVD case-patients by the timing of symptom onset (earlier vs later in the outbreak). We also explored differences in the number of health facilities visited by SVD case-patients who were known contacts and not known contacts before their symptom onset.

Qualitative interviews

For the qualitative component, we only considered case-patients with short and long times to effective isolation. We conducted qualitative interviews during November 2022 with case-patients in Kassanda District, where there were active SVD case-patients at the time of the investigation. We collected illness narratives from consenting surviving case-patients or relatives of deceased case-patients. We asked about factors that they felt facilitated or hindered the patient seeking and receiving rapid effective isolation. SVD case-patients were chosen purposively to have variation by age, sex, and being known contacts.

Interviews were conducted in either English or the local language, Luganda, depending on the participant’s preference, and recorded and transcribed verbatim. The accuracy and completeness of the transcription were verified by three members of the study team.

Data analysis

We analyzed quantitative data using Stata version 16.0. We evaluated the trend in time to effective isolation by week of symptom onset using the Mann-Kendall test for monotonic trends.

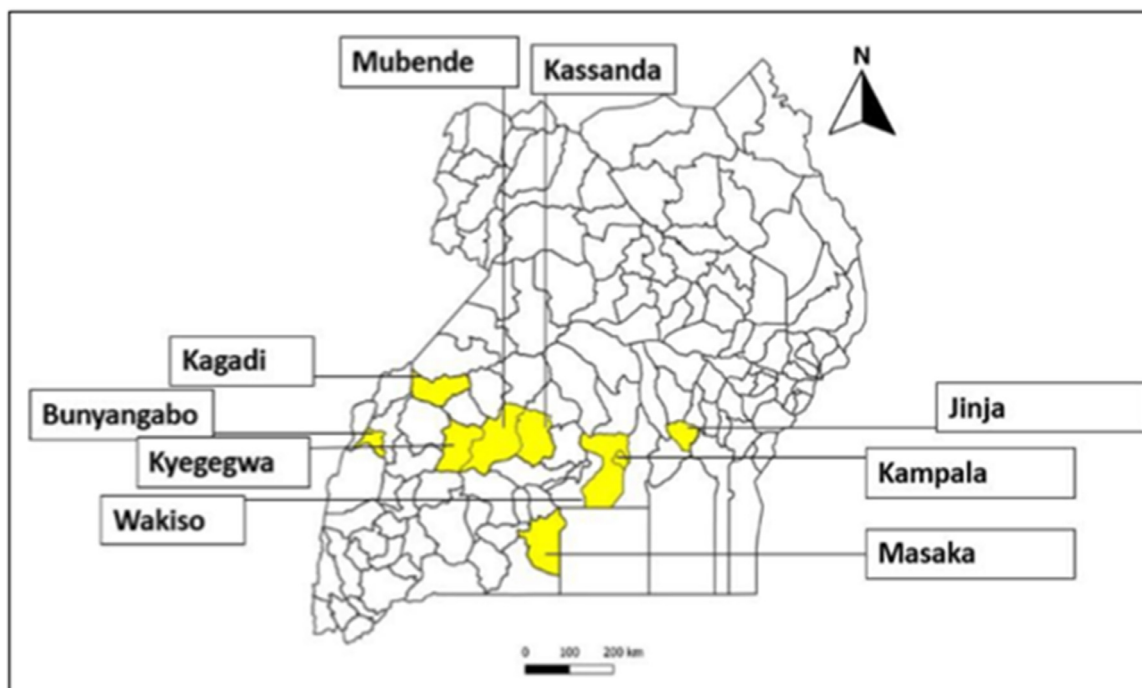


Figure 1. Map of Uganda showing the districts with SVD cases, September to November, 2022.

Table 1
Characteristics of 118 SVD case-patients with onsets from September 20 to November 30, 2022, in Uganda.

Characteristic	N	(%)
Age in years		
<5	6	(5)
5-17	15	(13)
18-40	76	(64)
>40	21	(18)
Sex		
Male	74	(63)
Female	44	(37)
Was a known contact (listed by contact tracing team before symptom onset)		
No	73	(62)
Yes	45	(38)
Timing of symptom onset during the outbreak		
Earlier	44	(37)
Later	74	(63)
District of residence		
Kassanda	46	(39)
Mubende	57	(48)
Kampala	18	(15)
Jinja	2	(2)
Masaka	1	(1)
Wakiso	3	(3)
Bunyangabo	1	(1)

We compared the median time to effective isolation in for case-patients with symptom onset earlier versus later in the outbreak using the log-rank test for trend. We also compared the median number of health facilities visited for case-patients whose symptom onset was earlier versus later in the outbreak, and for those who were and were not listed as contacts before symptom onset using the Wilcoxon rank-sum test. To determine factors associated with delayed time to effective isolation, we employed a generalized linear model using the Poisson family and log-link and reported robust standard errors. The reported measure of association was risk ratios with their 95% confidence intervals. We did not perform multivariable analysis due to small sample size.

For qualitative data, we employed inductive content analysis. The main themes indicating the perspectives of SVD case-patients or their relatives concerning the facilitators and barriers to early time to effective isolation were coded from interview transcripts after line-by-line analysis. To guarantee descriptive validity and consistency, the first author first analyzed the transcribed data before the two other authors independently reviewed it.

Quantitative results

Among 142 RT-PCR-confirmed SVD case-patients, we excluded 24 (1 fetal death and 23 with symptom onset before the SVD outbreak was declared). For the 118 SVD case-patients included, the median age was 30 (IQR, 22-38) years; most (63%) were male and 57 (48%) were from Mubende District (Table 1).

The median time from symptom onset to isolation at an ETU was 5 days (IQR 3-8). There was a general decrease in delays to effective isolation over time ($P = 0.04$). There was a longer median delay in the earlier versus later period of the outbreak (7 vs 5 days, $P = 0.03$) (Figure 2).

Fifty-one (43%) case-patients sought care from an ETU, 44 (37%) from a clinic/drug shop, 16 (14%) from a health center or hospital, and 7 (6%) from a traditional or religious healer, as the first healthcare point. Seeking care at an ETU first was much more common for case-patients who were known contacts, compared with those who were not known contacts (73% vs 25%). Known contacts visited a median of 1 (range, 1-4) health facilities before going to the ETU compared with those who were not known contacts (median 2, range 1-8) ($P < 0.0001$) (Table 2).

Of the 44 case-patients who had symptom onset earlier in the outbreak, 13 (30%) were isolated at an ETU or isolation facility as

the first healthcare point, compared to 38 (51%) of the 74 case-patients who had symptom onset later in the outbreak. Patients with onset earlier in the outbreak and later in the outbreak both visited a median of two (IQR 1-3) healthcare points ($P = 0.70$).

Of the 118 case-patients, 25 (21%) had effective isolation ≤ 2 days after onset, 43 (36%) 3-5 days after onset, and 50 (42%) ≥ 6 days after symptom onset. Having symptom onset earlier in the outbreak (crude risk ratio [cRR] = 1.8, 95% confidence interval 1.2-2.8) was associated with a higher risk of delayed effective isolation, compared with symptom onset later in the outbreak (Table 3).

Qualitative results

We conducted 17 in-depth interviews with 13 survivors and 4 relatives of deceased SVD case-patients. Eight (47%) interviewees were female. Twelve (71%) were aged 18-40 years, four (24%) were >40 years of age, and one (6%) was an emancipated minor.

Four major themes emerged as facilitators to short delays to care: knowledge of being a contact, knowledge of SVD signs and symptoms, belief and information that early treatment seeking will save a life, and encouragement and information from a trusted source.

1. Awareness of Ebola-related symptoms

Case-patients with short delays to effective isolation reported having received information from healthcare workers on the early symptoms of SVD and where to seek appropriate treatment (i.e., calling the alert lines or ambulance lines rather than going to a private clinic or other non-ETU health facility).

"It is the symptoms they told us (that made me think it might be Ebola)...the health workers (said) that if you begin to get a fever or you get dizziness..."

-Female case-patient with a short delay

Case-patients with long delays to effective isolation reported that they were unaware of the early signs and symptoms of SVD because the symptoms were similar to other common infections, like malaria and typhoid fever. They reported that the symptoms that made them suspicious were late SVD-related symptoms, particularly bloody diarrhea, vomiting, and bleeding from other body openings.

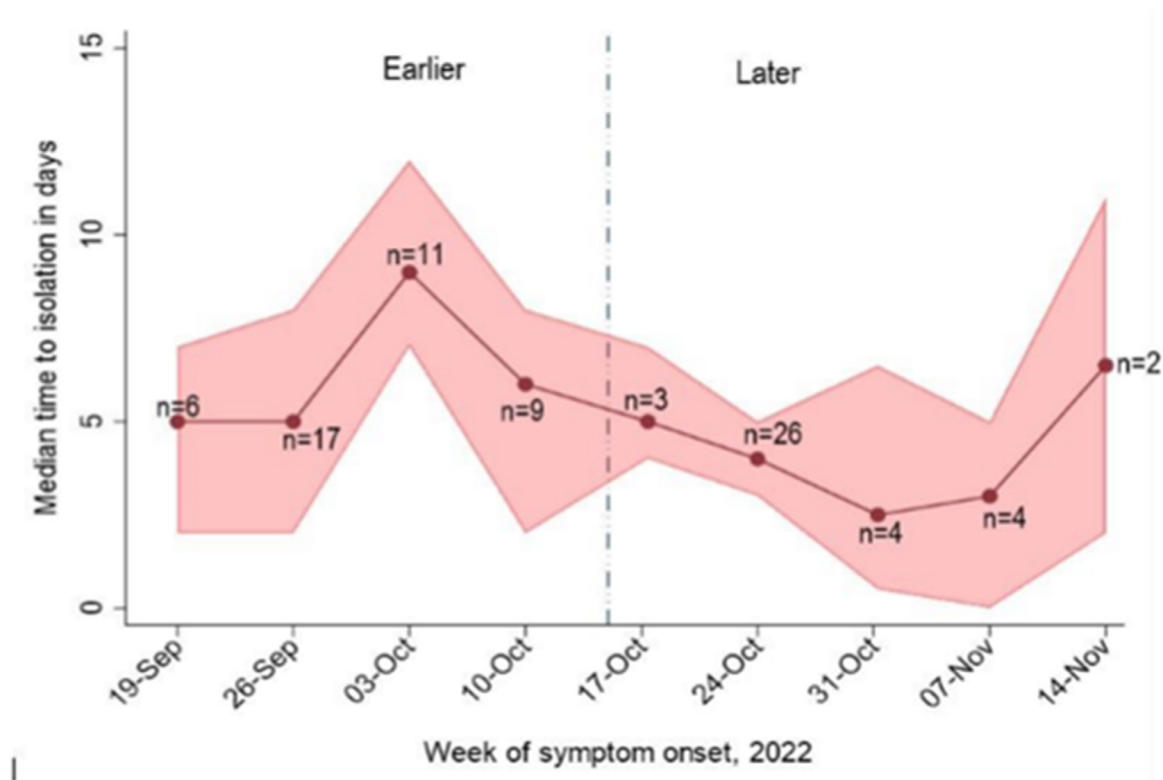


Figure 2. Median time from symptom onset to seeking effective isolation by the week of symptom onset. The shaded region represents the limits of the first and third quartile of time to seeking effective isolation for patients who had onset during that week.

Table 2

Order in which healthcare facilities were visited for care among 118 confirmed SVD case-patients in Uganda, September to November, 2022.

Order of visited healthcare points	Spiritual/traditional healer	Pharmacy	Private clinic	Admitting health center/hospital ^a	ETU/isolation facility
Care sought by all SVD case-patients					
1 st Healthcare point	7	12	32	16	51
2 nd Healthcare point	1	4	9	9	44
3 rd Healthcare point	1	1	2	3	16
4 th Healthcare point	0	0	2	2	3
5 th Healthcare point	0	0	1	0	3
6 th Healthcare point	0	0	0	1	0
7 th Healthcare point	0	0	0	1	0
8 th Healthcare point	0	0	0	0	1
Care sought by SVD case-patients listed as contacts before symptom onset, n = 45					
1 st Healthcare point	1	2	5	4	33
2 nd Healthcare point	0	0	1	2	9
3 rd Healthcare point	0	0	0	1	2
4 th Healthcare point	0	0	0	0	1
Care sought by SVD case-patients not listed as contacts before symptom onset, n = 73					
1 st Healthcare point	6	10	27	12	18
2 nd Healthcare point	1	4	8	7	35
3 rd Healthcare point	1	1	2	2	14
4 th Healthcare point	0	0	2	2	2
5 th Healthcare point	0	0	1	0	3
6 th Healthcare point	0	0	1	0	0
7 th Healthcare point	0	0	1	0	0
8 th Healthcare point	0	0	0	0	1

ETU, Ebola treatment unit.

^a Admitting health center/ hospital comprises health centers II, III, regional and private hospitals.

Table 3

Factors associated with delayed treatment seeking among 118 SVD case-patients in Uganda, September to November 2022.

	Not delayed (N = 68)		Delayed (N = 50)		cRR	95% CI
	n	(%)	n	(%)		
Age in years						
<18	15	(71)	6	(29)	0.68	0.33-1.4
18-40	44	(58)	32	(42)	Ref	
>40	9	(43)	12	(57)	1.4	0.86-2.1
Sex						
Male	41	(55)	33	(45)	Ref	
Female	27	(61)	17	(39)	0.87	0.55-1.4
Listed as a contact before symptom onset						
No	37	(51)	36	(49)	Ref	
Yes	31	(68)	14	(32)	0.65	0.40-1.1
Timing of symptom onset during the outbreak						
Earlier (before October 15)	18	(41)	26	(59)	1.8	1.2-2.8
Later (on or after October 16)	50	(68)	24	(32)	Ref	

cRR, crude risk ratio.

"I didn't know that the lady (with whom I had contact) died of Ebola. They thought she was sick with malaria or something else...So now after two days... I started feeling weak. I was feeling bad and my wife here said maybe we bring the doctor. I did not know what was the matter with me because it has been very long since I got malaria or sick! I am now clocking 53 years... I even reached a point and asked what was really hurting me.... and then they put me on a drip (IV medication at home)!"

-Male case-patient, long delay

2. Knowledge of being a contact

Interviewees noted that in addition to knowing the early symptoms of SVD, knowing that they were a contact of a confirmed SVD case-patient or had been exposed before their symptom onset was a major reason for early care-seeking. All those with short delays knew that they were a contact and thought their symptoms were suggestive of SVD. A participant noted,

"...the day I was told I was one of the contacts of the late [person] who had died of Ebola. It came to my mind, and I put it inside me that it could be true that the guy I was staying with, one of my friends had died of Ebola. I never took time to resist like other people did."

-Male case-patient, short delay

3. Encouragement and referral from a trusted source

Despite expressing fears about care-seeking, participants with short delays reported that encouragement from a trusted source like the village leaders, friends, relatives, and particularly from trusted healthcare workers in their communities encouraged them to seek ETU care early. A participant noted,

"...the doctor, who I know is the one who strengthened me, he told me to go to hospital and you will be treated, and I asked him, Doctor, they told us they kill people, then he said no, you go, (I) am your friend and have sent you there, go...that's why I got the strength and went."

- Female case-patient, short delay

4. Belief that early care-seeking is life-saving

All participants with short delays reported that they sought SVD care early primarily because they believed that it would increase their chances of survival. They reported that this information had been provided by community healthcare workers. They also reported that they had witnessed persons who went to the ETU in the late stages of the disease "with no energy left" who almost always died. This motivated them to seek care early. A participant said,

"The way I love my life! I couldn't miss visiting the hospital early...they said that if you delay to visit the hospital when you are infected with Ebola that you can seriously be affected and you can die, Dr. [Kizito] used to tell us."

-Male, short delay

Three key themes emerged as major barriers to short delays to effective isolation: low index of suspicion for EBOD among healthcare workers, fear of the ETU, and limited access to formal healthcare facilities.

1. Lack of healthcare worker index of suspicion for Ebola

The lack of suspicion among healthcare workers was the most commonly-reported issue reported by participants with long delays. All SVD case-patients with long delays had sought healthcare within 2 days of onset. However, the healthcare workers did not consider SVD as a possible diagnosis, even in this outbreak setting. A participant reported,

"So I was admitted (at the private clinic) and was being treated for typhoid with medicine through the vein for 4 days, but when it (typhoid) refused to heal, the healthcare worker told me that the dose is over but you are not improving, go to the ETU."

-Male case-patient, long delay

2. Fear of the ETU

Fear of what takes place inside the ETU was reported in nearly all interviews by participants with both short and long delays to effective isolation. Fear was never a single barrier to care-seeking; in persons with long delays, when fear was presented in the narrative, it was also in the context of the lack of referral by healthcare workers.

A participant noted,

"Patients would call here and tell people at home (that in the ETU) there's hunger, they don't eat. As you know how people can say bad things, that they inject them and take their body parts."

-Male case-patient with a long delay

Reports of delays in taking blood samples for Sudan Ebola Virus testing and release of test results—resulting in some suspected case-patients staying in a "holding area" for suspected cases for several days—dissuaded some people from seeking early care. Participants noted that the process of arrival and testing at the ETU was poorly explained, and that they felt confused when some patients in the holding area first tested negative and then tested positive. They additionally perceived that the ETU had insufficient numbers of healthcare workers.

"I asked her (the patient in the ETU) to give the phone to any healthcare worker in the ETU but she said there was no one. She told me that there wasn't a single healthcare worker or anyone in the ETU and that she was there alone."

– Caregiver of the patient (fatal case) with a long delay

"I have tested two times and I'm negative. By the time they discharge me, they know I'm negative... they called me the next day (saying)...Oh, we are very sorry the results turned out to be positive and we are going to send an ambulance to come and pick you up. I said what is this, I was very scared...."

–Male case-patient, short delay

"The ambulance came and took me (to the ETU)...I realized nobody is attending to me (in the holding area), doctors (health workers) are jumping me going to the other patients. My head is getting confused and I am not understanding some things. I reached a point and told the police officer to let me go home so that I get someone who can take care of me."

–Male case-patient, long delay

Despite these reports, the surviving case-patients had overall positive perceptions of the quality of care.

"I don't regret anything, only I'm so thankful for the Ministry of Health, for the care they gave us, the treatment they are giving us. The doctors, care they gave us. For sure I think God should bless them."

–Male case-patient, short delay

Although it is often suggested that survivors can support community dialogues to motivate care-seeking for other patients in their communities, most survivors reported risking stigmatization and accusations for speaking positively about care.

"But he (our friend) died...there was no health worker around the time he died...What hurt me was that his mom confirmed that her child was just killed (in the ETU)...we can't go against that (mother's word)...that health workers killed her child. Yet for us, we know the truth... that they treated him... but we cannot say different... or they say we are against them."

–Male, long delay

3. Limited access to health facilities

In some situations, case-patients reported that limited access to formal healthcare facilities stopped them from seeking care. Participants cited challenges with a lack of money to obtain transportation to a formal healthcare facility.

"What made them (the patient) to visit the (formal) health facility, it's me who gave them the money, because when you have the money, you reach early where you are going, so we saw her when she was not feeling well, then we said you never know it may be true that it could be Ebola because the situation she was in was alarming.."

– Relative of a female survivor

Discussion

During the 2022 Sudan virus outbreak in Uganda, only one in five patients received care early. Patients with onset later in the outbreak had decreased the risk of delayed care. Patient knowledge about early SVD symptoms and trust in the benefits of early care facilitated early presentation, as did encouragement from a trusted source to go to the ETU. Financial constraints and recognition of early SVD symptoms by healthcare workers were barriers to early receipt of SVD care.

Late presentation for SVD patients puts both the community and the patient at increased risk: for the patient, later presenta-

tion decreases their chance of survival [15], and provides additional opportunities to infect his or her contacts [16,17]. In this outbreak, delays shortened considerably as the outbreak progressed. This likely reflects both an increased index of suspicion by healthcare workers and/or an increasing willingness in the community to seek ETU care. It is also possible that the lockdown during October–December could have increased the community's perceived risk of infection and disease severity [18,19], potentially leading to more rapid healthcare seeking. Ultimately, the shortened time to isolation likely contributed to outbreak control; the last confirmed case in the outbreak was identified in November 2022.

Both patients and caretakers reported that healthcare workers had a low index of suspicion for SVD. Particularly in the early stages of an EBOD outbreak, this may be unavoidable; the clinical presentation of EBOD is similar to common febrile infectious diseases, such as malaria or typhoid [20]. This presents a clear opportunity for improved response in future outbreaks. Standard operating procedures for EBOD outbreaks indicate that all persons should be screened for nonspecific and EBOD-related symptoms as well as possible epidemiologic links to confirmed EBOD cases by healthcare workers before entry into any health facility, and suspected cases should be isolated and tested. Early institutionalization of this process in all health facilities in affected areas could both serve to increase the healthcare worker index of suspicion and potentially help protect the community [20].

Being identified as a contact of a confirmed EBOD case-patient was an important reported factor influencing time to effective isolation by heightening contacts' suspicion of SVD. Being informed about the early symptoms, the benefits of early care-seeking, and where to seek care, they were more likely to call helplines. A community-led Ebola action approach in Sierra Leone showed that continuous communication with communities about EBOD resulted in reduced time to isolation [21]. Employing this approach early and often in EBOD outbreaks may reduce overall time to isolation among patients. This points to the crucial interplay between knowledge of early nonspecific EBOD symptoms, knowledge of being a contact of a confirmed EBOD case and early care seeking by communities [20].

Encouragement from a trusted person facilitated early effective isolation. Although EBOD survivors can motivate care-seeking for other community members [22], in Kassanda District, survivors were sometimes mistrusted. Information exchange and referral from trusted members of the family or community are important drivers for healthcare seeking, especially in fragile health systems [23,24]. Indeed, mistrust of the healthcare system and fear of the ETU was a major barrier to early effective isolation. Other studies have reported similar findings [25]. Early risk communication led by trusted members of communities could facilitate improved early care-seeking for SVD patients.

Reports (and rumors) about the ETU, especially early in the outbreak, may have driven people to seek care elsewhere first. However, a lack of knowledge about SVD, lack of referral from healthcare workers, and a lack of transport to seek care from the appropriate facility were additional barriers. As a result, patients often visited other healthcare providers, including traditional healers, who were closer. The propensity to visit traditional healers for health issues is common in African settings [26,27]. More active case-finding and constant, ongoing training of staff at lower-level facilities as well as traditional healers and religious leaders might facilitate earlier presentation to care.

This study had some limitations. First, there is a possibility that the healthcare providers or facilities visited before the ETU—particularly traditional or religious healers—were under-reported due to social desirability bias. Second, we did not adjust for confounders due to the small sample size which could have biased our results from the quantitative component of this study. In addi-

tion, the qualitative interviews represent the perspectives of case-patients from Kassanda District and may not be generalizable to other SVD case-patients across the country.

In conclusion, few cases were isolated early after symptom onset in the 2022 SVD outbreak in Uganda. Delays in effective isolation were reduced for patients with onset later in the outbreak. Individual and health facility factors influenced time to effective isolation. Community sensitization, led by trusted members of the community rather than EBOD survivors, may be more effective in fostering trust in the public health system for future outbreaks. Refresher trainings for healthcare workers in the public, private, and informal health sectors on preparedness for EBOD could reduce the time to isolation of case-patients in future EBOD outbreaks. The allocation of essential resources, such as food and medicine, by Ebola-specific response teams in ETUs, could enhance community perception and trust in the EBOD response efforts.

Declarations of competing interest

The authors have no competing interests to declare.

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Ethical considerations

We sought permission to conduct the study from the Ministry of Health, District Health officer, as well as the chairpersons and village health officers of the given villages. We obtained verbal consent from participants of the qualitative component. This activity was reviewed by CDC and was conducted consistent with applicable federal law and CDC policy. § See e.g., 45 C.F.R. part 46, 21 C.F.R. part 56; 42 U.S.C. §241(d); 5 U.S.C. §552a; 44 U.S.C. §3501 et seq.

Availability of data and materials

The datasets upon which our findings are based belong to the Uganda Public Health Fellowship Program. For confidentiality reasons, the datasets are not publicly available. The datasets can however be availed upon reasonable request from the corresponding author with permission from the Uganda Public Health Fellowship Program.

Disclaimer

The findings and conclusions in this report are those of the author(s) and do not necessarily represent the official position of the U.S. Centers for Disease Control and Prevention.

Authors Contribution

RA: Participated in the conception, design, analysis, interpretation of the study and wrote the draft manuscript; BNS, MWW, SRA, SKN, MN, AK, ARA, DK, BK, RM, LB, HNN, JFZ, BA, ZK, MGZ, PK, TK, PCK, DNG, IBK, IA, AA, SE, EJN, VM, SMM, PN, RN, AK reviewed the report, reviewed the drafts of the manuscript for intellectual content and made multiple edits to the draft manuscript; MC, TL, and JRH reviewed the manuscript to ensure intellectual content and scientific integrity. JRH also participated in the conception, design, analysis, interpretation. All authors read and approved the final manuscript.

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