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"I just haven't experienced anything like this before"

A qualitative exploration of callers' interpretation of experienced conditions in telephone consultations preceding a myocardial infarction

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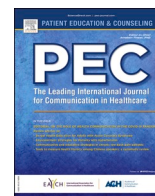
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“I just haven’t experienced anything like this before”: A qualitative exploration of callers’ interpretation of experienced conditions in telephone consultations preceding a myocardial infarction

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ABSTRACT

Objectives: Callers with myocardial infarction presenting atypical symptoms in telephone consultations when calling out-of-hours medical services risk misrecognition. We investigated characteristics in callers’ interpretation of experienced conditions through communication with call-takers.

Methods: Recording of calls resulting in not having an ambulance dispatched for 21 callers who contacted a non-emergency medical helpline, Copenhagen (Denmark), up to one week before they were diagnosed with myocardial infarction. Qualitative content analysis was applied.

Results: Awareness of illness, remedial actions and previous experiences contributed to callers’ interpretation of the experienced condition. Unclear symptoms resulted in callers reacting to their interpretation by being unsure and worried. Negotiation of the interpretation was seen when callers tested the call-taker’s interpretation of the condition and when either caller or call-taker suggested: “wait and see”.

Conclusion: Callers sought to interpret the experienced conditions but faced challenges when the conditions appeared unclear and did not correspond to the health system’s understanding of symptoms associated with myocardial infarction. It affected the communicative interaction with the call-taker and influenced the call-taker’s choice of response.

Practice Implications: Call-takers, as part of the decision-making process, could ask further questions about the caller’s insecurity and worry. It might facilitate faster recognition of conditions warranting hospital referral.

1. Introduction

Telephone triage is a globally utilized practice and plays a central role in identifying urgent medical problems in out-of-hours medical services [1,2]. Telephone triage, which is performed by nurses and

physicians [1], constitutes a complex setting where the call-taker’s primary source of information is the caller’s verbal descriptions of symptoms. Therefore, the outcome of the call relies on the caller’s ability to describe the experienced condition [3–5]. While identification of an approaching myocardial infarction (MI) is challenged by several callers

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experiencing atypical MI presentation, for example no chest pain[6–8], a correct triage screening is complicated by callers experiencing and describing symptoms differently than the medical literature [9–11]. Lack of correct triage affects the chance of survival amongst these callers [9].

The correct assessment of the severity of reported conditions is influenced by descriptions of unclear symptoms by the caller, and the absence of a primary problem [11], thus emphasizing the challenges callers are facing when experiencing an approaching MI. First, they need to recognize a need for help by making an interpretation of the experienced condition and second, they must describe the experienced condition when consulting health professionals to gain access to treatment in the hospital.

Help-seeking behaviour among patients suffering from MI is well documented [12–15]. However, less is known about how callers express their interpretation of experienced conditions in communication with health professionals in those cases, where callers' condition did not result in hospital referral. Exploring the communication between caller and call-taker in telephone consultations provides information for improving identification of callers suffering a MI less easily recognized.

Therefore, this study aimed to explore what characterized callers' interpretation of experienced conditions where an approaching MI was not initially recognized, and how the conditions were described in the telephone consultations by the callers. Only after repeated contact with the Copenhagen emergency medical services (EMS), the callers were referred to the hospital and diagnosed with MI.

2. Methods

2.1. Theoretical approach

A system theoretical approach was applied to explore callers' attempt to interpret the experienced condition through communication with call-takers [16,17]. According to Luhmann [18] interpretation and construction of meaning are interrelated, given that every construction of meaning is an interpretation. Following this understanding, it is exclusively through observation of the communicative interaction that it is possible to gain access to the communicating parties' interpretation of the experienced condition [16,18]. Furthermore, telephone consultations only make it possible for the call-taker to understand the caller's experienced condition through communication understood as verbal and nonverbal utterances. Non-verbal utterance can be the sound of breathing or vocal tone. As a result, the call-taker is predominantly dependent upon the caller's interpretation of the body's condition [18]. To identify people with illness, a distinction is made between illness and health. This distinction is made by means of a program that, among other things, consists of diagnostics and symptom descriptions [18,19]. The call-taker "translates" the caller's experienced condition into symptoms using electronic decision-support tools. To visualise the distinction between the caller's descriptions and the call-takers "translation", experienced conditions represent the caller's utterances.

2.2. Setting

The study was carried out using recorded phone calls to the 1813-medical helpline (MH) in 2018 using callers diagnosed with MI within the coming week. The MH is operating 24-hours a day all year as a part of the Copenhagen EMS and can be contacted in case of non-emergency medical conditions [20]. The call-takers are guided by a locally developed electronic decision support tool [21], and can offer guidance in the form of 'self-care', 'watchful waiting', recommend medical attention by visiting the general practitioner, or refer to emergency departments. Nurses and physicians are employed as call-takers. Physicians are specialists in general medicine or internal medicine and nurses have broad nursing background with at least five years of work experience. In addition, nurses complete a training program [22].

Callers diagnosed with MI within seven days after the last call to the Copenhagen EMS were identified in the Danish National Patient Registry [23]. Linkage across different registries is made possible through the Danish Civil Registration Number, a unique personal identifier distributed to all Danish citizens [24]. Records of the telephone consultations were stored at the Copenhagen EMS and potentially relevant calls were identified linking information from an administrative database at the Copenhagen EMS and information from the Danish National Patient Registry.

2.3. Data collection

Overall, we focused on callers who had been in contact with Copenhagen EMS at least twice in the week before they were diagnosed with MI to examine characteristics in caller's interpretation of the experienced condition prior to hospitalization. All selected callers had up to the last call been triaged to 'self-care' or 'watchful waiting' and only in their last call they were offered hospital referral and later diagnosed with MI, according to ICD-10 classifications, in the hospital (Fig. 1.).

¹Copenhagen emergency medical services.

²No electronic audio recording of the last contact available.

³Myocardial infarction.

In the administrative database at the Copenhagen EMS information about the telephone consultation is linked to the patient's Civil Registration Number. This even when the caller is not necessarily the patient but a relative or a bystander. In the following analysis 'caller' is used as a joint denomination regardless of whether the caller is the patient, relative or a bystander.

2.4. Data analysis

After transcribing the selected telephone consultations verbatim, they were entered into Nvivo (QSR International). Qualitative content analysis with subsumption strategy was applied where main categories were generated, referring to the research question combined with the theoretical approach, and subcategories were generated based on concepts of the material [25]. Patient, caller, and call-taker were identified, allowing the communication to be analysed. Information on gender and age were obtained from the Danish Civil Registration Number, and we registered the first reported condition by the caller as the reason for calling. The analysis was carried out by the first author (BJ). Building the coding frame and the pilot analysis were discussed with experienced researchers (HVN, HB) leading to modifications in the coding frame. The amount of material included in the analysis is determined by the point where more material does not generate new insights or categories [25]. This point was reached with the 21 callers.

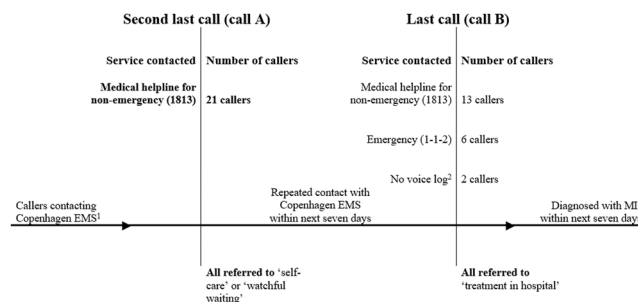


Fig. 1. Timeline of contact to the Copenhagen EMS, including call-taker's chosen response prior to MI diagnosis. Left side of the vertical lines illustrates which service is contacted and right side of the vertical lines illustrates the number of callers who contacted each service.

2.5. Ethical considerations

According to Danish legislation, Research Ethical approval for registry-based studies is not required [26], thus no informed consent was provided. This study complies with the Declaration of Helsinki and was approved by the data responsible authority, Capital Region (Approval number: P-2019-191), and the Danish Patient Safety Authority (Case number: 3-3013-2795/1, reference: EMGW). Due to ethical considerations all participants in the telephone consultations were anonymized in the transcripts.

3. Results

We analysed communication in call A (Fig. 1.) among 21 callers with 28 calls (Table 1), who had been in contact with the Copenhagen EMS at least twice up to one week before they were diagnosed with MI.

Overall, an equal proportion of the callers described having experienced a sudden onset of a new condition or suffering a well-known condition. There was no clear pattern in the reason for calling (Table 2).

Given the perception of telephone consultation as a meaning-constituting interaction system three main categories, together with seven subcategories, were generated to explore elements involved in the callers' interpretation of their experienced condition, as it was observed in the communication between caller and call-taker (Fig. 2).

The first main category included aspects related to the caller's attempt to interpret the experienced condition. In the second main category, the caller's reaction to the attempt to interpret the experienced condition was analysed. Lastly, the third main category analysed how telephone consultations contained elements of negotiation. An illustration of the coding frame is shown in Table 3.

3.1. Factors contributing to caller's interpretation

3.1.1. Awareness of illness

Among one-third of the callers, possible heart diseases or heart-related symptoms were not part of the interpretation of the experienced condition either by the caller or by the call-taker during the telephone consultation. In several cases, the callers explicitly dismissed heart-related conditions, because they argued that the experienced condition was not consistent with well-known symptoms associated with heart disease. Elliot mentioned: "...I hardly dare to say, if it had only been the left arm, then I would immediately be afraid if it was something heart related, but it's not, it is both arms and it hurts like crazy". In Alex's case his wife explained: "I immediately thought of the heart department [wife

Table 1 Characteristics of patients, callers and analysed telephone consultations.

	Number of patients = 21 Number of telephone consultations including transfer of calls from nurse to physician = 28*
Age of patients, years	
Mean	68
Median	72
Range	45-90
Male patient, n (%)	12 (57)
Caller, n (%)	
Patient	22 (79)
Relatives	6 (21)
Patient participating in the call	26 (93)
Duration of call, min	
Mean	05:03
Median	04:45
Range	01:20 - 11:40

* Seven out of 21 patients have two calls linked to call A because a nurse responds but transfers the call to a physician. In the administrative data at the Copenhagen EMS, it is registered as two separate calls.

Table 2 Information on patients, callers, and telephone consultations.

Pseudo name	Age ^a	Gender	Role of the caller	Justification for calling ^b	Reason for calling - first reported condition by caller ^c
Alex	70 – 79	Male	Wife	Sudden onset of new condition	Pain below sternum
Andrew	50 – 59	Male	Patient	Suffered for several days	Something reminiscent of heartburn
Anna	70 – 79	Female	Husband	Sudden onset of new condition	Stomach ache, chest pain, and vomiting all night
Becca	80 – 89	Female	Patient	Suffered for several days	Extreme pain in shoulder [...] in the right shoulder
Bert	50 – 59	Male	Wife	Sudden onset of new condition	Unwell together with chest pressure and tingling in the arms
Camilla	40 – 49	Female	Husband	Sudden onset of new condition	Nerve pains in the back
Cole	70 – 79	Male	Patient	Sudden onset of new condition	Backpain together with pain in the left shoulder
Clara	80 – 89	Female	Patient	Sudden onset of new condition	Worried due to high blood pressure
Collin	70 – 79	Male	Patient	Sudden onset of new condition	Intense pain in the left chest region and pain in the shoulder
David	60 – 69	Male	Patient	Suffered for several days	Intense pain around the solar plexus
Elliot	60 – 69	Male	Patient	Deterioration of condition	Extreme pain in the arm
Elsa	50 – 59	Female	Patient	Deterioration of condition	Earache
Edward	40 – 49	Male	Patient	Deterioration of condition	Problems with bronchi together with flashes of chest pain
Jeremy	70 – 79	Male	Patient	Sudden onset of new condition	Myalgia in the back and the chest
Laura	70 – 79	Female	Patient	Sudden onset of new condition	Suddenly unwell
Lisa	70 – 79	Female	Patient	Deterioration of condition	Fighting for breath
Mike	70 – 79	Male	Wife	Sudden onset of new condition	Fit of coughing
Oliver	40 – 49	Male	Wife	Unchanged condition	Intense pain caused by stomach acid
Rianna	90 – 99	Female	Patient	Suffered for several days	Heartburn
Sophia	70 – 79	Female	Patient	Sudden onset of new condition	In shortness of breath
Tom	60 – 69	Male	Patient	Suffered for several days	Pain in the legs

^a Intervals of 10 years.

^b Justification for calling the Copenhagen EMS before the patient was diagnosed with MI.

^c First reported condition by the caller, where caller is a joint denomination regardless of whether the caller is the patient, relative, or a bystander, to the Copenhagen EMS before the patient was diagnosed with MI.

addressed Alex], but there is no radiation to the neck or arms, is there?". This was dismissed by Alex. In some cases, callers explicitly mentioned possible heart disease when trying to interpret the experienced condition. However, the call-taker dismissed possible heart disease based on the information uttered by the caller. When Collin asked directly about possible heart disease the call-taker answered: "No, then you wouldn't sound so well. So, I don't believe in that". In other cases, callers dismissed

Table 3 (continued)

Context units ¹	Units of coding ²	Subcategory	Main category
kind of panic when it starts to hurt, and you don't know what the hell is going on Call-taker: yes		insecurity, being scarred or nervous	
David: okay ... it's because I wondered whether it was pneumonia or something like that Call-taker: no, no otherwise you wouldn't sound this way. If it were pneumonia, you would constantly be coughing Call-taker: the question is how long it's [high blood pressure] going to stay up there. Try to sleep and wait and see if it's better tomorrow	"Okay ... it's because I wondered whether it was pneumonia or something like that" "Try to sleep and wait and see if it's better tomorrow"	Caller tests call-taker's interpretation of condition Definition: The category applies if the caller discusses the call-taker's interpretation of the experienced condition Postponement of evaluation of severity Definition: The category applies if either call-taker or caller suggests waiting and see	Negotiation of interpretation Definition: Based on the concept-driven understanding of telephone consultations as interaction systems, the category includes the aspect of negotiation in the caller's interpretation of the experienced condition Negotiation of interpretation

¹ Context units are the surrounding material needed to understand the meaning of a unit of coding [25].

² Units of coding are the part of the text that fits within one subcategory [25].

together with a need to construct meaning in the experienced condition was explicitly expressed by most of the callers. Overall, unclear symptoms were seen as a common reason for callers to be unsure of the interpretation, which led to frustration. Becca declared: *"I'm not getting anywhere just by talking, I don't know what it is!"*. Other callers found it difficult to determine the severity of their experienced condition. Edward explained: *"I don't really know what's wrong... it seems serious, but I can try taking some painkillers and then wait and see... and if it continues, I will have to call you again"*. Some callers explicitly sought out guidance from the call-taker. Lisa stated: *"That won't do, what am I to do?"*. Bert's wife expressed uncertainty several times given Bert's unclear symptoms and ended up asking the call-taker: *"So, I don't know... what would your advice be?"*. And Oliver's wife suggested it would be in vain to increase Oliver's analgesic intake but ended the conversation with: *"but you know that better than I do"*. Furthermore, contacting the Copenhagen EMS was seen as a precaution by the caller, caused by unclear symptoms. Laura, who had a sudden onset of feeling unwell, stated several times: *"I'm calling just to be sure"*.

Challenges with interpretation were also expressed in hesitation as to when it would be appropriate to contact the Copenhagen EMS. Following this, it was important for the call-taker to emphasize the caller's justification for calling. Bert's wife explained: *"I would have done that [called immediately] if I wasn't unsure..."*, to which the call-taker answered: *"...well of course, you have to call, absolutely...we completely agree on that"*. In Cole's case, it was his visiting family who talked him into calling the MH, and Cole stated: *"[...]we don't want to make a fool of anyone"*, the call-taker answered: *"nobody is a laughing stock here, you can always call... you can call with big and small problems, and we will find out how we can help in the best way, that's our mission"*. Other callers were

more persistent in their considerations to contact the MH. Elliot stated: *"I was just about to give up on calling you, but then I thought I'd better check it out just as a precaution"*.

3.2.2. Worry

Worry was a common theme among several callers. Worry was expressed both in relation to a specific symptom and in relation to the interpretation of the experienced condition. Worry, as an expressed reaction, was shown when the callers stated that they were feeling concerned, insecure, panicked, scarred as well as nervous. Bert had been biking with his son and was feeling unwell after returning home. His wife told the call-taker that they were concerned partly, because Bert had not felt like this before and because of the unclear symptoms not easily fitting into the well-known understanding of symptoms related to heart disease. Clara stated: *"I'm a little insecure about the blood pressure, because of the high level"*. Edward explained: *"maybe it's some kind of panic when it starts to hurt, and you don't know what the hell is going on"*. Laura mentioned several times: *"I got a bit scared, because I haven't experienced this before"*.

The call-takers used different approaches when callers expressed uncertainty of the interpretation or if they were worried. In some cases, the expressed insecurity or worry did not facilitate further communication, as the call-taker only asked questions about symptoms. In other cases, the call-taker actively considered the information in the decision-making process, by either inviting the caller to take part in the decision-making or recommended the caller to call again if the caller experienced something similar or if certain symptoms appeared. The call-taker asked Edward: *"Do you feel safe with this [watchful waiting] or would you rather go to the hospital right away?"*. The call-taker emphasized to Alex: *"If you feel a pressure behind the breastbone, radiation, breathing difficulties or dizziness you call immediately"*.

3.3. Negotiation of interpretation

3.3.1. Caller tests call-taker's interpretation of condition

Discussing the call-taker's interpretation was seen among several callers, however, it did not change the call-taker's initial interpretation. In Anna's case the call-taker interpreted the condition as food poisoning, but Anna argued: *"but none of the others have that"*. David described intense pain around the solar plexus as a reason for calling, leading the call-taker to interpret the condition as: *"It sounds like you have copious amounts of stomach acid"*, even though David rejected having heartburn or vomiting when asked by the call-taker about symptoms associated with excess gastric acid. David responded: *"Okay ... it's because I wondered whether it was pneumonia or something like that"*. This was dismissed by the call-taker due to a lack of symptoms applicable to pneumonia.

3.3.2. Postponement of evaluation of the severity

Postponing decision-making about the severity of the condition was seen when either the call-taker or caller suggested to 'wait and see'. This was seen among half of the callers, all of whom reported an onset of a new condition together with reporting conditions not easily fitting into the health system's understanding of severe conditions warranting hospital referral (Table 1). In Alex's case, the call-taker decided: *"I think we should just wait and see [...] before we do a whole lot urgently"*. The call-taker recommended Clara, who was concerned with her high blood pressure; *"Try to sleep and wait and see if it's better tomorrow"*. Cole explained: *"I think I will just go and see my doctor tomorrow"*. Elliot took the initiative for evaluating his condition to which the call-taker concluded: *"Well, it's difficult to figure this one out. With something like this, we usually say that there can be several causes. So, there is not just one, but several"* indicating an acknowledgment of the complexity in the experienced condition. Elliot's ability to enter a communicative negotiation led to the call-taker suggesting an 'assessment track' at the hospital, however, Elliot declined, stating: *"No, I think we will just wait and*

see". Call-takers often ended the telephone consultations by recommending the callers to call again if the condition deteriorated.

4. Discussion and conclusion

4.1. Discussion

Help-seeking callers with an unrecognized impending MI seek interpretation of the experienced condition during their telephone consultations. The lack of recognition causes insecurity and worry when the experienced condition appeared unclear.

The finding that worry was a common emotion in the telephone consultations, and was expressed differently by the callers, are in line with Gamst-Jensen et al. [27]. Patients' interpretation of the urgency of their experienced condition, expressed as degree-of-worry, is found to be associated with hospitalisation within 48 h after their first contact to the MH [28]. It has been argued that the decision-making process around choice of response could be improved by incorporating callers' interpretation of the severity of the experienced condition [27,29]. If this approach was implemented amongst the callers in our study, it might have resulted in hospital referral sooner, as several of the callers expressed worry in relation to their condition.

According to Luhmann [30], the function of the health system is to contribute to health, and its benefit to ill people is treatment. The distinction between disease and health structures the communication between health professionals and callers. Following this understanding, the function of the MH can be regarded as to interpret whether callers are describing conditions equivalent to symptoms warranting hospital referral. Our study shows that callers may have difficulty "translating" experienced conditions into symptoms consistent with the call-taker's expectations, especially when the symptoms appeared unclear. According to guidelines, complex conditions must be assessed by a physician [22]. Several of the telephone consultations in our study resulted in transfer of the call from a nurse to a physician within the MH (Table 1), emphasizing the complexity of the caller's experienced condition.

Suspicion of MI qualifies as a potentially life-threatening condition and the recommendation is to contact the EMS to receive rapid assistance [31]. Instead of turning to the EMS, several callers subsequently diagnosed with MI consult non-emergency medical services as their first medical contact [32–34]. The callers in our study chose a similar approach as they contacted a non-emergency medical helpline, and several callers had seen their general practitioner before calling the MH.

Awareness of possible heart disease was present among most of the callers but did not lead to hospital referral. It is well-established that patients without chest pain are at risk of being misdiagnosed and undertreated [8,35]. Most of the callers did not report chest pain, and among the few callers who did, it was not the focus of attention in the communication between caller and call-taker.

Telephone triage is a well-established approach in prehospital settings, but relies upon effective decision support tools [1]. Regardless of the fact that call-takers do not necessarily see decision support tools as prohibiting professional expertise [36], the callers are at risk of being misdiagnosed when the triage depends on the decision support tools and when callers describe conditions beyond the rationale of the decision support tools. Our findings illustrate this shortcoming. Performing decision-making on the severity of a condition in a setting without visual cues is a well-known challenge in telephone triage [3–5,37]. Call-takers develop skills to handle telephone consultations without being able to see the caller by gathering accurate information about descriptions of location of symptoms and listening for physical signs [4]. These techniques were also seen in our study, where callers were asked to describe the exact location of pain. While symptom presentation and description of symptoms were not interpreted as severe at first by both caller and call-taker, our study illustrates how difficult it can be for the caller to interpret the symptoms and communicate the experience to a health professional in a comprehensive way. This challenge emphasizes the

limitations in the set-up of telephone consultations, where callers are implicitly expected to be able to decide which information is relevant in the interpretation of symptoms that they have not experienced before.

It has previously been found that patients are concerned about "bothering" the doctor [34]. Similar concerns were expressed in our study when several callers described uncertainties as to when it was appropriate to seek help. Our findings revealed compassionate call-takers, who reassured the callers that contacting the MH was the right thing to do.

We did not identify patterns between gender or age and descriptions of symptoms adding to the complexity in identifying an approaching MI. Other authors [35,38–40] found descriptions of MI symptoms presentation differ based by gender or age.

A strength of this study is the use of 'real time' information, which removes the risk of the subjects not being able to remember what had happened or relying on the recollections of survivors. Even though we had no access to the thoughts behind callers' and call-takers' interpretation of the condition, we gained information by observing the communication together with information on subsequent MI. We selected callers who were referred to 'watchful waiting' or 'self-care' in the call to Copenhagen EMS as a comparable referral independently of caller characteristics or who the call-taker was.

A limitation of our study is the lack of indication of diagnostically relevant symptoms. Further research designed as a comparison study is relevant to determine the clinical relevance of our findings. The call-takers' communicative approaches are an important aspect of the communicative interaction in telephone consultations. We are examining the call-taker's decision-making process in another, ongoing analysis.

4.2. Conclusion

The findings revealed how the callers sought to interpret the experienced condition but were facing challenges when the experienced condition appeared unclear to the call-taker, leading to insecurity and worry in the caller. The interpretation of the experienced condition was further challenged by descriptions of symptoms not easily fitting into the health system's understanding of symptoms related to an impending MI. It affected the communicative interaction with the call-taker and influenced the call-taker's choice of response.

4.3. Practice implications

The call-takers in prehospital telephone consultation settings must be aware that the caller does not have any aids, neither previous experiences nor a professional understanding of concepts, which can lead to insecurity and worry in callers when the condition does not appear straightforward from a medical perspective. If call-takers asked further questions about the caller's insecurity and worry, as part of the decision-making process, it might facilitate faster recognition of conditions warranting hospital referral.

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CRediT authorship contribution statement

Study design and data analyses: BJ, HVN and HB. Data acquisition: SNB and FF. Data collection: BJ and EHAM. Validation of the transcript accuracy: HVN. Revision of the coding process: BJ, HB and HVN. Generation of the first draft of the study manuscript: BJ. Manuscript preparation and revision for important intellectual content: All other authors. Funding acquisition: CTP, HB, FF and KK.

Informed consent and patient details

We confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

Declaration of Competing Interest

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