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Diagnosis of Rare but Dangerous Diseases in Primary Telephone Consultation

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Abstract

Primary telephone consultation provides the patient with the opportunity to make a phone call and receive medical information between the onset of the first symptoms of the disease and their first visit to the doctor. This creates an opportunity to speed up the moment when the patient receives the first qualified help and thereby increases the success of further treatment. This is especially important in the case of the so-called "must not miss" diseases. These are the most dangerous, albeit rare, diseases in which early detection and treatment is a decisive factor in the success of treatment. However, telephone consultations can also create new problems, the most important of which is related to the fact that in such process the doctor has only the data that can be obtained by interviewing the patient. This is fraught with an increased risk of medical error. This danger is especially great in the case of "must not miss" diseases, in which only at the very early stage there are serious chances to stop the progression of the disease.

The article discusses ways to solve this problem – the requirements that must be met by the organisation of a consultation in order to maximise the use of the possibilities of telephone consultation in these conditions for the timely detection of "must not miss" diseases. The problems of harmonising these requirements with the organisational and economic conditions in which telephone consultation is carried out are discussed.

Keywords: doctor's responsibility, primary telephone consultation, rare but dangerous diseases.

Introduction

Primary medical telephone consultation is a service that gives everyone the opportunity to call and get medical advice (Leite et al., 2020; Hjelm, 2005; McKinstry et al., 2010).

The primary consultant is the only doctor with whom the patient can consult at a very important moment: the very beginning of his disease. It is the time between the patient's first symptom and his first visit to the doctor. For the patient, this is the time when they are still painfully hesitating: to see a doctor immediately or hope everything will improve on its own. They are torn between the fear of raising the alarm in vain and the fear that they have a deadly disease. They consult with every friend, try to sort the conflicting information they find on the Internet out, and rush from one extreme to another.

At this time, the consultant is the only angel-saviour to show them the right path.

It is also important that a call to the primary consultation allows to speed up the moment when the patient receives their first qualified assistance.

The initial telephone consultation allows the patient to immediately receive the most necessary, and most importantly, qualified conferencing about their problem; while in order for a regular visit to the doctor to take place, the patient needs numerous time expenditures, often removing this visit for a long time: an appointment with a doctor, days and weeks until the moment when the doctor can see the patient, the distance to visit the doctor and back, waiting in line, and the like. Finally, telephone consultation is incomparably more cost-effective, both for the patient and the facility (Bergmo, 2014). All this opens up new opportunities for increasing the cost-effectiveness and success of treatment and new prospects for improving its quality.

However, primary telephone consultations also bring problems (Katz et al., 2008; Bunn et al., 2004; Hildebrandt, 2006). When interviewing the patient who called, the consultant must determine whether there are grounds to suspect that the patient has any disease and, if so, give the patient appropriate recommendations. These tasks are not easy even during a face-to-face visit when the doctor can not only interview but also examine the patient, as well as use data on their current and past diseases, research data, and treatment from their medical records. In contrast, in the case of telephone consultation, the consultant is limited to only the data that can be obtained during the interview. When consulting by phone, the consultant does not have access to the patient's medical records, and does not have data on their current and past illnesses. The consultant cannot also examine the patient. Therefore, they have to base their conclusions only on the data they can obtain from the patient's responses.

The risk of medical error is high in normal face-to-face interaction with a doctor. It increases significantly in the case of a telephone consultation, in conditions of very limited information about the patient. The problem is further exacerbated by the fact that the responsibility of the doctor in case of failure to detect such a disease, in the case

of telephone consultation, in principle, is no different from the responsibility in the case of a face-to-face visit.

Thus, telephone consultation, on the one hand, opens up opportunities to improve the effectiveness of patient care. On the other hand, the price for this opportunity is quite high – an increase in the risk of error and the associated harm to the patient.

All this is especially important in the case of the so-called "must not miss" ("red flag") diseases. These are the most dangerous diseases, in the treatment of which early detection and treatment of the disease is a decisive factor in successful treatment, while at the further stages of the disease the ability to help the patient is greatly reduced (Ramanayake et al., 2018; Sanges et al., 2020; Sujitha et al., 2022).

Such a disease, as its very name says, "should not be missed" – should be suspected already at the first visit of the patient to the doctor. The consultant must first make sure that the patient does not have signs of any of the "must not miss" diseases. If such a disease is detected only at the later stages of the disease, when the opportunity to effectively help the patient will already be missed, the question immediately arises whether all the possibilities for its timely detection have been used by the consultant and if not all, then, accordingly, about their responsibility for incomplete usage.

In Lithuania, in 2000–2018, court cases related to the fact that a dangerous and urgent disease was not detected on time and as a result, the patient died or suffered damage to their health account for the majority of cases for compensation for damage to the patient's health (Labanauskas et al., 2010).

The requirement to use all possibilities fully applies to the telephone consultation. During the interview, the consultant should take all measures to identify symptoms of a possible dangerous disease that requires urgent action.

The most important of these measures in the case of "must not miss" diseases is the timely detection of signs that make it possible to reasonably suspect such a disease. However, in "must not miss" diseases, detection is often associated with additional difficulties. Firstly, the vast majority of such diseases are less common (hence another name for these diseases – "rare but dangerous") and, accordingly, the doctor may not have sufficient experience in their detection. Secondly, at the initial stage, such diseases are most often manifested by nonspecific symptoms characteristic of the most common and non-dangerous diseases.

Therefore, a necessary condition for their timely detection is a "high level of vigilance", when the doctor makes every effort to check whether there are symptoms that would reasonably suspect "not to miss the disease" (Porter, 2008; Stern et al., 2020).

The issue of "not to be missed" is central to the problems associated with the introduction and expansion of telephone consultations in general. It is the "can't miss" diseases that pose a major threat to the reliability of such counseling. A review of studies on the reliability of telephone consultations (Huibers et al., 2011) showed that they are generally correct at 86.7–90.2 %. Yet, this figure drops to 46 % in the case of rare but dangerous diseases (10 high-quality studies).

All this makes addressing the "must not miss" problem central to telephone counselling, the "key" to the wider use of primary telephone consultations. This promising form of patient care will spread if the organisation and methodology of counselling ensure the identification of symptoms in its course that make it possible to reasonably suspect a "must not miss" disease.

Unfortunately, the problem of identifying "must not miss" diseases in the course of telephone consultations has not yet attracted due attention. Information search for publications on this topic has been carried out. PubMed's database of medical publications, covering 34 million medical publications, was searched using the keywords: "must not miss disease" OR "red flag disease" OR "rare but dangerous disease" OR "must not miss condition" OR "red flag condition" OR "rare but dangerous condition" AND "telephone consultation" OR "remote consultation". The search revealed 20,293 publications dealing with either these diseases or remote (including telephone) consultations, but none were found dealing with these diseases concerning just telephone consultations.

Traditionally, telephone consulation is most often seen as primarily intended for mild cases that do not require special attention. It is assumed that a patient with a potentially serious and dangerous illness does not use a telephone consultation, but goes directly to the doctor. This idea contradicts the fact that in reality, a significant part of such diseases debuts with non-specific and in many respects typical for the most frequent and non-dangerous disease symptoms. Simultaneously, symptoms specific to a dangerous disease may be mild, hardly noticeable, and their detection may require special attention of the doctor.

This means that it is at this primary stage that everything that is necessary to identify the symptoms of "must not miss" diseases should be provided. Therefore, the first priority of a telephone consultation is not to help in mild cases but to timely respond to dangerous ones.

Thus, the preparation of a consultant, the organisation and implementation of a telephone consultation should, first of all, ensure timely detection of any signs of "must not miss" diseases. The presence or absence of such signs is the first thing the consultant should do after listening to the patient and asking clarifying questions.

The purpose of this article is to clarify the requirements for the education of a consultant and the organisation of a consultation that allow them to cope with this task.

In the following sections of the article, three requirements for a telephone consultation that ensure the detection of "must not miss" diseases will be discussed.

1 First Requirement: Full Differential Diagnosis of Patient's Complaints

For any complaint of the patient, for any symptom they mention, the consultant must have the full list of "must not miss" diseases that may be hiding behind such symptom. Medical diagnostic textbooks and handbooks discussing the main symptoms

that patients most often present with symptoms can be caused by one or many "must not miss" diseases (Porter, 2008). Thus, headaches can be not only a manifestation of a wide variety of common diseases, but also a "must not miss" series (Porter, 2008; Stern et al., 2020).

Therefore, in listening to the patient and the symptoms they mention, the consultant should think not only of the most likely given symptoms but of all possible rare but dangerous diseases. Here it is necessary to emphasise the word "all". Indeed, if the doctor forgets about any of these diseases, the forgotten one may well be the exact one that the patient has.

The consulting physician should be provided with a complete list of "must not miss" diseases for each of the symptoms encountered during the consultation. Counselling protocols should require the clinician to review each symptom reported by the patient to check for the presence or absence of all "must not miss" diseases that may present with the symptom.

2 Second Requirement: "All Questions Must Be Asked"

Description of any "must not miss" disease in the textbook, as a rule, contains many symptoms. However, at the initial stage, such a disease is likely to show some of them. Those may be the only basis to suspect a dangerous disease. Therefore, the doctor must ask all questions that can reveal the symptoms of this disease. Only in this case there is a guarantee that those will be set that allows one to reasonably suspect "must not miss" disease in this case.

Hence, when checking whether there are any symptoms that may indicate a "must not miss" disease, it is necessary to ask all questions for each possible disease, aimed at identifying all possible symptoms. Each of these questions should be considered as "not to miss symptom".

Therefore, for each "must not miss" disease that may be hidden behind the patient's complaint, the consultant must also have a complete list of its symptoms that can be identified during the questioning.

3 Third Requirement: Reasonable Correlation between Duration of Consultation and Its Content

Telephone consultation should ensure that the consultant has sufficient time to complete the first and second requirements. As stated above, if a patient comes to a telephone consultation with a health complaint, the consultant should do two things:

1) According to the first requirement, he should consider every "must not miss" that may be hidden behind this complaint;
2) According to the second requirement, he must check for the presence or absence of every symptom of each of these possible "must not miss" diseases.

For instance, in a case where a symptom reported by the patient can be caused by five different "must not miss" diseases, and each of them can be manifested by 10 different symptoms, such patient must be asked at least 50 questions (5 diseases × 10 symptoms = 50 questions).

The process of telephone consultation involves the patient listening to the question, them thinking about it and then answering the question. The doctor may need to ask further clarifying questions and discuss the answer with the patient. Considering that all this may require at least one minute, the total patient interview should take 50 minutes. This further means that the consultant will interview no more than 8 patients per shift. However, from an economic and managerial point of view, the consultation cannot take as long. Modern health care is squeezed in the tight grip of economic restrictions. Studies of the duration of telephone consultations have shown that they are much shorter than is necessary to ask all required diagnostic questions. Moreover, they are much shorter than the usual face-to-face consultations. Studies have shown that a telephone consultation lasts on average about five minutes and does not exceed 10 minutes (Mohammed et al., 2012; McKinstry et al., 2010).

The world practice of telephone consultations is also based on the premise that such counselling should be short, and the counsellor's conclusion is based on several questions. The most popular sets of counseling protocols, such as Julie K. Briggs (2021), David A. Thompson, Barton D. Schmitt, Sheila Wheeler contain a strictly limited number of questions and focus on the most common illnesses.

Thus, the consultant has only a fraction of the time that they need to reliably detect "must not miss" diseases. Therefore, during the time allotted for a consultation, they do not have time to do everything that is necessary for the timely detection of such diseases, and at least some of them will be missed.

This is fraught with very serious consequences for both the patient and the doctor. It is obvious that the doctor-consultant is faced with the need to look for ways to solve this problem – to find ways not to miss the "must not miss" symptoms of the disease, despite the lack of time.

One of the ways to resolve this conflict is to focus on the most probable diseases. The consultant focuses their attention on the most likely, most common diseases in their daily practice and uses the limited consultation time available to check if there are signs of one of them. In this case, "must not miss" diseases, as rarer ones, are out of their attention, since there is not enough time to detect them. This approach is best expressed by the well-known medical wisdom that says: "If you hear a clatter of hooves, think of a horse, not a zebra" (Goldstein, 2012). This "horse, not zebra" approach is widespread in everyday medical practice and ensures its ability to adapt to equally widespread limitations of time resources.

The implications of such an approach need to be considered as well. A symptom that can be caused by a variety of diseases, among which one is dangerous, requires immediate response; fortunately, situations like this are rare, occurring in one out of

a thousand cases. If the doctor, due to lack of time or for other reasons, is guided by the "horse and zebra" rule and does not check whether there are signs of this disease, the probability is very high (999 out of a thousand) that the specialist will not be mistaken and that the rare disease symptom in reality does not exist. Moreover, they may encounter this symptom 998 more times and again will not be mistaken. However, in one out of 1000 cases, the "horse and zebra" rule will still naturally lead them to an error, which, due to the danger of this disease, will have serious consequences for the patient and for the doctor.

In every case, such an error is unlikely (only one chance in a thousand). However, throughout their career, the doctor examines many thousands of patients and may encounter such symptom many thousands of times. Therefore, with this approach, they are "programmed" to make a mistake and harm the patient and the right that follows from all this new responsibility. When a chance does bring the doctor to such a patient and the doctor misses the "must not miss" signs of the disease, they will be accused of being negligent and therefore not checking for signs of a dangerous disease.

In fact, the error will unlikely be caused due to negligence, but rather due to the fact that the doctor has followed the established and in most cases justified practice. This practice has evolved due to the limited duration of the consultation, which in turn reflects limited economic conditions. This practice is fraught with negative consequences for both the patient and the doctor. The most important consequence for the patient is late diagnosis, missed treatment opportunities, and, as a result, damage to health.

The second consequence is loss of confidence in the doctor and medicine. The patient expected the doctor to be able to diagnose any disease. No one warned them that by turning to a telephone consultation, they can only count on identifying the most common diseases. Therefore, the doctor's mistake is considered by the patient as inability or unwillingness of the doctor to fulfil their duties.

The consequence for the doctor is that he is found guilty of what they have no blame in, namely, that they follow the common practice. The mistake is not due to their negligence or lack of qualification, but to the fact that they have been unlucky and the case has brought them to a patient who has a rare "must not miss" disease.

The second way is diagnostic identification of rare diseases. During the interview of the patient, several symptoms are revealed, which together add up to a picture of a certain disease, which the doctor immediately recognises. This recognition is immediate and frees the physician from having to check all other suspicions. Therefore, it allows diagnosis or at least suspecting a "must not miss" disease in the shortest possible time.

The possibility of such "recognition" is supported by numerous studies showing the prevalence of such practice in everyday medical practice (Japp et al., 2018). In the case of time and data limitations typical of telephone counselling, such instant "identification" should play a particularly important role. Unfortunately, in rare diseases this diagnostic approach is ineffective. The doctor recognises diseases that are encountered quite often. This will not work in the case of a rare disease that the doctor will encounter only a few

times during their career. In addition, "identification" works best if they meet a typical, textbook-described picture of the disease and the entire set of characteristic symptoms is observed. Unfortunately, such a typical and complete picture appears only in the later stages of the disease, when it manifests itself "in full force". Meanwhile, in the case of dangerous but rare diseases, it is required to establish the disease at the earliest stage when the chances of stopping or slowing down its progression are highest.

The implications of this approach are identical to those of the first. The patient expects the doctor to diagnose any disease, not just ones that manifest themselves with typical symptoms and are well "recognised". Therefore, in this case, the doctor's mistake is considered by them as the inability or unwillingness of the doctor to fulfil their duties. In this case, the law places all the blame for the fact that a dangerous disease was not detected promptly on the doctor. The fact that rare, "must not miss" diseases that occur only a few times throughout a career are poorly recognised and not carefully considered.

The third way is to spare time by using the doctor's medical intuition and practical experience. In conditions of limited time, an experienced doctor often intuitively feels the right direction in the search for disease. This feeling helps them narrow their search considerably and immediately suspects the disease that has caused the observed symptom. Telephone consultation is precisely the case when, due to limited time and data, medical intuition should play a particularly large role. However, this approach does not solve the problem of early detection of "must not miss" diseases. Of course, in the course of a telephone consultation, medical intuition can suggest the correct diagnosis immediately. However, the law requires correct diagnosis not sometimes but in every single case. In some cases, intuition may not suggest the correct diagnosis. Moreover, whether intuition works or not depends on the will of the doctor; it is a spontaneous process. Therefore, the doctor's legal responsibility for the results of this spontaneous process, independent of their will, is very problematic. As a result, this approach generates the same consequences as the previous two. On the one hand, this is damaging and deceives legitimate expectations of the patient; on the other hand, it supposes laying responsibility on the doctor for something that does not depend on their will – inability to perform all the actions (ask all the questions) necessary to reliably identify symptoms of rare but dangerous diseases because of restricted consultation time.

The once wise Don Quixote, instructing Sancho Pancho on how to fulfil the role of governor, said: "*Most importantly, Sancho, never issue laws that your loyalist cannot comply with.*" The responsibility of the doctor in all the considered approaches violates this establishment. The doctor has duties that exceed their ability and responsibility for events that they are unable to prevent.

Totality of the consequences of excessive legal requirements is known as "defensive medicine". These are measures by which the doctor is protected from impracticable legal requirements and the unjustified liability arising from them (Sekhar & Vyas, 2022). Measures of "protective medicine" include avoiding any more or less responsible decisions,

prescribing unnecessary tests and drugs, avoiding (unjustified referral to other doctors) any embarrassing cases.

In the case of telephone consultation, a manifestation of "defensive medicine" is a direct or indirect refusal to consult a patient. This is, firstly, a direct recommendation to completely abandon the initial telephone consultation, and use it only in further treatment when the patient has already been examined, the diagnosis is clear and the patient just needs to clarify the details of the treatment (Katz et al., 2008; Bunn et al., 2004; Hildebrandt et al., 2006). This creates an opportunity for the doctor to avoid risks and responsibilities that they face during the initial telephone consultation. However, this is achieved at a high price – giving up all the opportunities that telephone consultation creates.

Secondly, it is an indirect avoidance. In this case, the initial consultation is still carried out; however, the same fear of the consultant doctor to miss a dangerous disease during a brief telephone conversation with the patient often prompts the doctor to turn the consultation into a non-specific, non-binding introduction to the subsequent referral to the doctor. This approach means giving the appearance of a telephone consultation without actually taking advantage of its benefits.

The main solution to these problems should be a clear definition of the boundaries of the real possibilities and responsibilities of the doctor in the course of telephone consultations. This requires that the consulting physician be held responsible only for those actions that he can actually perform. For this, in turn, it is required that the range of diseases be accurately established, including "must not miss", which can be identified in the conditions of a telephone consultation within the time allocated for such counselling. The patient who seeks consultation should be warned about the limits of the doctor's diagnostic possibilities. They should have access to information about the signs of which "must not miss" diseases are checked during the consultation and which ones can remain out of the doctor's attention. The patient should also have access to information about alternative ways of obtaining information that they cannot obtain during a telephone consultation.

Conclusions

1. Initial telephone consultation opens new prospects for improving the quality, accessibility and cost-effectiveness of medical services. However, it significantly increases the risk of medical errors, both diagnostic (the disease that is actually the source of the patient's complaints may not be suspected) and therapeutic (incorrect recommendations).
2. The main source of medical errors during consultations are rare, but dangerous ("must not miss" diseases) require immediate response.
3. To ensure the reliability of a telephone consultation, the counsellor must have a complete list of "must not miss" diseases, the symptoms of which occur during counselling.

4. For each of these "must not miss" diseases, there should be a complete list of symptoms that can manifest at an early stage.
5. Based on these lists, it is necessary to establish the time required to check for the presence of symptoms of each of the possible "must not miss" diseases.
6. Based on an assessment of available resources and the danger and rarity of each "must not miss" disease, it is necessary to determine whether the available resources allow for the time necessary to detect it and, accordingly, whether it can be included in the list of diseases that can be identified or suspected during a telephone consultation.
7. To clarify "must not miss" diseases is rather complicated due to their extreme rarity, less danger and limited opportunities for telephone consultations.
8. Lists of "must not miss" diseases, identification of which during telephone consultation cannot be ensured, should be available to everyone who applies for such consultation. These individuals should be informed where they can go for advice on non-listed conditions.
9. The consultant cannot be held liable for not detecting signs of a disease that are not among the "must not miss" diseases for which the consultation provides verification of the presence of their signs.

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