

# The Consistency of Medical Information on Internet

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*Abstract:* Author conducted the review of several Internet based information sources which combine symptoms and underlying causes (diagnoses, diseases). The base was the experience with the Mayo Clinic portal for patients <https://www.mayoclinic.org/symptoms2>. It was found that the view to this information is not consistent in relation to the other-way-around view in <https://www.mayoclinic.org/diseases-conditions>, where in one symptom description all related diseases (diagnoses) should be listed. The symptom mentioned can be seen in “diseases view” (diagnosis “Amyloidosis”). The opposite “symptoms view” for “weight loss” does not yield diagnosis “amyloidosis” in the list of dozens of diagnoses listed. In Mayo Clinic portal this inconsistency is overall practice: the same applies for “amyloidosis” also for the symptom “leg swelling” etc, but also for other diagnoses and symptoms. Author further examined other popular health portals: WebMD 3, MSD-Priručnici 4 (Croatia), PatientsLikeMe6 and NHS5. Based on this research the finding was unanimous: there is obvious lack of consistency between categories symptoms and diseases/conditions. In addition, in almost every source mentioned, inconsistencies in terminology were observed. Author concludes that the cause of this shortcoming are obviously two separate sources of information: separate databases for diagnoses and another for symptoms. Therefore, the author finally recommends fixing these shortcomings. Implementing such improvements, “diagnosing wandering” can be substantially reduced, being advantageous for obtaining straightforward path in diagnostic process in many cases.

*Key words:* Case study; Amyloidosis on portal of Mayo Clinic

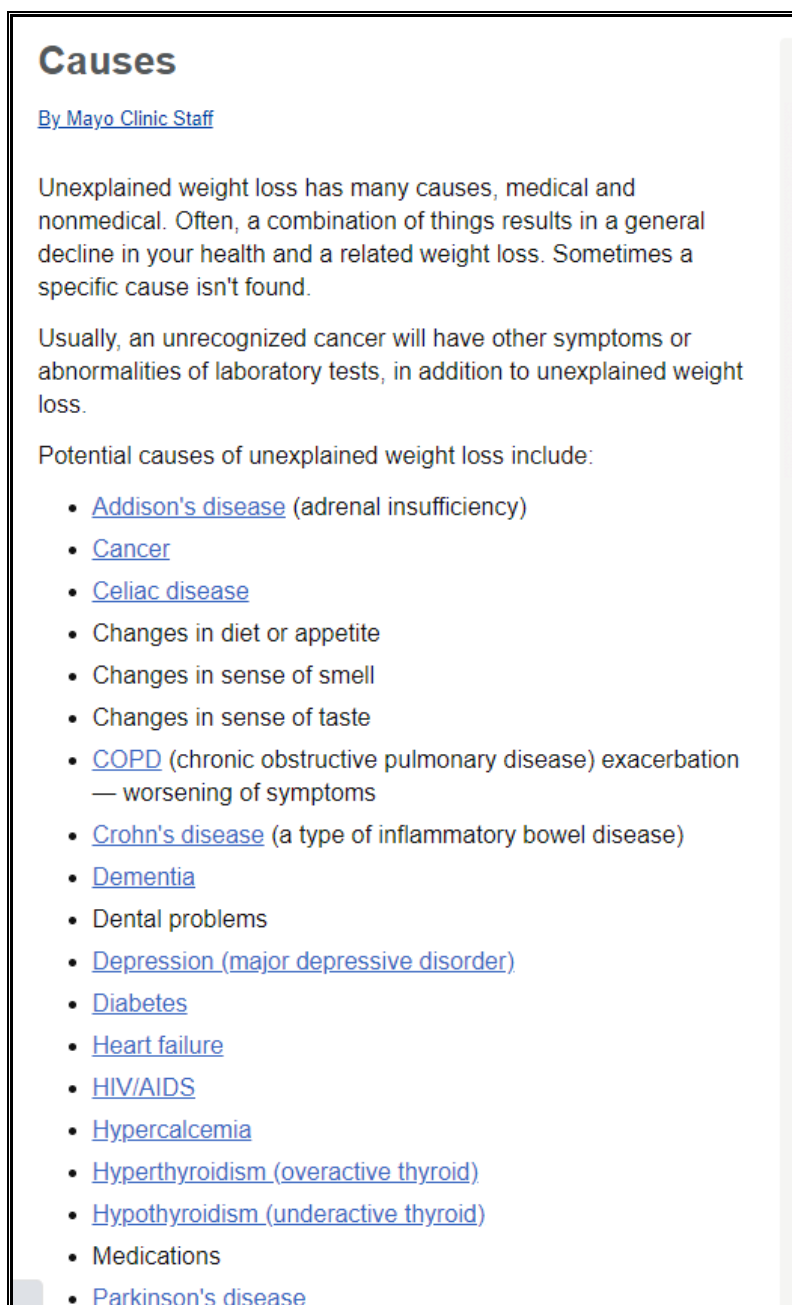
## Introduction

This research was induced by a very concrete medical case: at the beginning patient reported severe unexplained weight loss. This was followed by long lasting diagnostic process, conducted in very different directions, including colonoscopies and major surgery of bowels after suspicion on cancer. This final procedure and following histopathology finding turned out to be negative. After experiencing renal failure, the kidney biopsy was performed with consequent complications. This specimen turned out the amyloidosis as diagnose. Because of known association to multiple myeloma. patient was forwarded to haematology. There the multiple myeloma was diagnosed, which was underlying cause of secondary amyloidosis. Belated diagnose and treatment start (7-8 months after detecting symptoms) caused severe and partially non recoverable multiple organs damaging.

Author was personally involved in search for possible causes of unexplained weight loss, consulting among other sources also <https://www.mayoclinic.org/symptoms/unexplained-weight-loss/basics/causes/sym-20050700>. In this single instance of inconsistency observed, author was focused on the association between:

- Diagnosis “Amyloidosis” and
- Symptom “Unexpected weight loss”.

The symptom mentioned can be seen in “diseases view” (diagnosis “Amyloidosis”). The opposite “symptoms view” for “weight loss” does not yield diagnosis “amyloidosis” in the list of dozens of diagnoses listed.



**Causes**

[By Mayo Clinic Staff](#)

Unexplained weight loss has many causes, medical and nonmedical. Often, a combination of things results in a general decline in your health and a related weight loss. Sometimes a specific cause isn't found.

Usually, an unrecognized cancer will have other symptoms or abnormalities of laboratory tests, in addition to unexplained weight loss.

Potential causes of unexplained weight loss include:

- [Addison's disease](#) (adrenal insufficiency)
- [Cancer](#)
- [Celiac disease](#)
- Changes in diet or appetite
- Changes in sense of smell
- Changes in sense of taste
- [COPD](#) (chronic obstructive pulmonary disease) exacerbation — worsening of symptoms
- [Crohn's disease](#) (a type of inflammatory bowel disease)
- [Dementia](#)
- Dental problems
- [Depression \(major depressive disorder\)](#)
- [Diabetes](#)
- [Heart failure](#)
- [HIV/AIDS](#)
- [Hypercalcemia](#)
- [Hyperthyroidism \(overactive thyroid\)](#)
- [Hypothyroidism \(underactive thyroid\)](#)
- Medications
- [Parkinson's disease](#)

Figure 1. Screenshot from Mayo Clinic “Symptoms A-Z” chapter for the entry: “Amyloidosis”, from: <https://www.mayoclinic.org/symptoms/unexplained-weight-loss/basics/causes/sym-20050700> , (accessed May 2nd , 2021)

In Mayo Clinic portal this inconsistency is overall practice: the same applies for “amyloidosis” also for the symptom “leg swelling” etc. In addition, inconsistency in naming the symptoms (as well as other entities) was detected.

Unfortunately, among 23 possible causes of this symptom listed, amyloidosis was NOT mentioned at all (Figure 1. ).


It is understandable that all symptoms can not be mapped completely with all associated diagnoses, especially if the very rare disease is in concern, like secondary amyloidosis. But in this case, such “excuse” cannot be accepted: after obtaining respective diagnosis, Mayo Clinic portal was consulted again, with the result depicted in the Figure 2.

## Symptoms


You may not experience signs and symptoms of amyloidosis until the condition is advanced. When signs and symptoms are evident, they depend on which of your organs are affected.

Signs and symptoms of amyloidosis may include:

- Swelling of your ankles and legs
- Severe fatigue and weakness
- Shortness of breath with minimal exertion
- Unable to lie flat in bed due to shortness of breath
- Numbness, tingling or pain in your hands or feet, especially pain in your wrist (carpal tunnel syndrome)
- Diarrhea, possibly with blood, or constipation
- Unintentional weight loss of more than 10 pounds (4.5 kilograms)
- An enlarged tongue, which sometimes looks rippled around its edge
- Skin changes, such as thickening or easy bruising, and purplish patches around the eyes
- An irregular heartbeat
- Difficulty swallowing



**Purpura around the eyes**



**Enlarged tongue**

Figure 2. Screenshot from Mayo Clinic “Diseases & Conditions A-Z” chapter for the entry: “Amyloidosis”, from: <https://www.mayoclinic.org/diseases-conditions/amyloidosis/symptoms-causes/syc-20353178>, (accessed May 2nd, 2021)

In addition, Mrs. Dana Sparks, MD, associated to the Mayo Clinic published back in 2019. the following article: <https://newsnetwork.mayoclinic.org/discussion/what-is-amyloidosis-and-10-signs-you-might-have-it/><sup>8</sup>, where we find also “unintentional weight loss”, even as the third frequent/important symptom:

*“Unintentional, significant weight loss. If you're losing protein from your blood, you may lose your appetite and, as a result, lose weight without trying. If amyloidosis affects your digestive system, it can also affect your ability to digest your food and absorb nutrients. It's common to lose 20 to 25 pounds.”*

Author correctly directs the patients to the following:

*“Many of these signs and symptoms may be caused by other conditions. But if you experience any of them, talk with your health care provider about whether they might be caused by amyloidosis.”*

Primary aim of this paper is to point on inconsistencies in symptoms/diseases mapping as well as to propose solution for it. Of course, secondary objective is to make medical information on Internet more secure and useful for both patients and health care providers.

## Materials and methods

Based on the patient medical record presented in introduction, research was made on following internet portals/sites/platforms which render the service “symptoms checker” or similar:

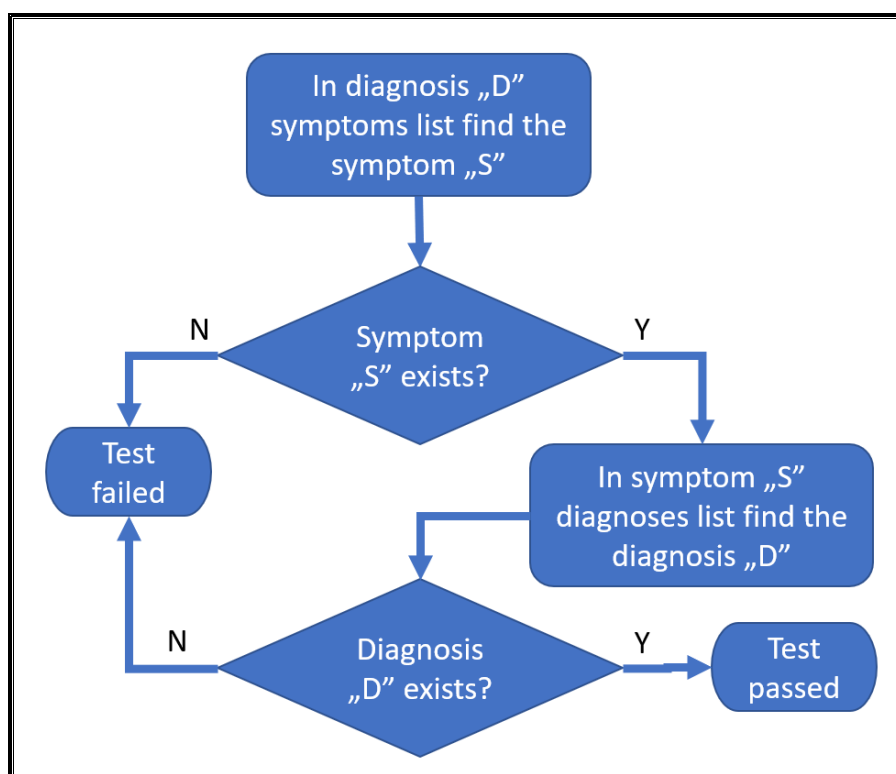
1. Mayo Clinic: <https://www.mayoclinic.org/symptoms>
2. WebMD: <https://symptoms.webmd.com/>
3. MSD (Croatia): <http://www.msd-prirucnici.placebo.hr/msd-simptomi>
4. NHS: <https://www.nhs.uk/conditions/unintentional-weight-loss/>
5. PatientsLikeMe: <https://www.patientslikeme.com>

„Material“ mentioned was analysed according to the aim of this paper: mapping between symptoms and diagnoses. This analysis was made in both directions:

1. First the symptoms were found in diagnosis (disease, condition) description, and
2. Subsequently these symptoms descriptions were checked against diagnoses.

This “test” resulted in “passed” if the same symptom/diagnosis pair was found in both searches. Otherwise, the “test” resulted with “fail”. Analysis process is shown in Scheme 1.

Of course, the focus was on the instance in medical record described in introduction (unintentional weight loss and amyloidosis). Some lateral symptom/diagnosis pairs were also examined, aimed to evidence general in/consistency of that sort.



*Scheme 1. Testing process of symptoms/diagnoses mapping*

## Results

According to the materials and methods described, here the results are presented, for each and every web page examined and tested against consistency of symptoms/diagnoses mapping.

From the Table 1. we see that there are different kinds of inconsistency. Either diagnose is not mentioned in the symptom's description page, or the symptom mentioned in diagnosis page is not existent in the symptoms list. The wording (naming) of symptoms is also inconsistent. Here we observed not less than six different wordings:

- “Unintentional weight loss” (in amyloidosis chapter13)
- “Unexplained weight loss” (in symptoms list entry14)
- “Unexpected weight loss” (in Esophageal cancer description15)
- “Unintentional, significant weight loss” (in Dana Sparks' paper8)
- “Weight loss” (in sarcoidosis chapter, even directing on “Obesity”11)
- “Losing weight without trying“ (Lung cancer chapter12)

Table 1. Symptoms mentioned in “amyloidosis” chapter of Mayo Clinic web site and their appearance in its symptoms’ chapter (causes list for specific symptom, from: <https://www.mayoclinic.org/diseases-conditions/amyloidosis/symptoms-causes/syc-20353178> (accessed May 2nd, 2021)

Symptoms mentioned: <a href="https://www.mayoclinic.org/diseases-conditions/amyloidosis/symptoms-causes/syc-20353178">https://www.mayoclinic.org/diseases-conditions/amyloidosis/symptoms-causes/syc-20353178</a>	Response in <a href="https://www.mayoclinic.org/symptoms">https://www.mayoclinic.org/symptoms</a>
1. Swelling of your ankles and legs	<a href="https://www.mayoclinic.org/symptoms/leg-swelling/basics/causes/sym-20050910">https://www.mayoclinic.org/symptoms/leg-swelling/basics/causes/sym-20050910</a> : amyloidosis not mentioned  Ankle swelling: symptom does not exist
2. Severe fatigue and weakness	<a href="https://www.mayoclinic.org/symptoms/fatigue/basics/causes/sym-20050894">https://www.mayoclinic.org/symptoms/fatigue/basics/causes/sym-20050894</a> : amyloidosis not mentioned  Weakness: symptom not mentioned in the symptoms list
3. Shortness of breath with minimal exertion	<a href="https://www.mayoclinic.org/symptoms/shortness-of-breath/basics/causes/sym-20050890">https://www.mayoclinic.org/symptoms/shortness-of-breath/basics/causes/sym-20050890</a> : amyloidosis not mentioned
4. Unable to lie flat in bed due to shortness of breath	symptom does not exist
5. Numbness, tingling or pain in your hands or feet, especially pain in your wrist (carpal tunnel syndrome)	<a href="https://www.mayoclinic.org/symptoms/numbness-in-hands/basics/causes/sym-20050842">https://www.mayoclinic.org/symptoms/numbness-in-hands/basics/causes/sym-20050842</a> : correct mentioning of amyloidosis  Symptoms such as tingling or pain in your hands or feet, especially pain in your wrist (carpal tunnel syndrome) were not mentioned in the symptoms list.
6. Diarrhea, possibly with blood, or constipation	<a href="https://www.mayoclinic.org/symptoms/diarrhea/basics/causes/sym-20050926">https://www.mayoclinic.org/symptoms/diarrhea/basics/causes/sym-20050926</a> : correct mentioning of amyloidosis  Constipation: symptom not mentioned in the symptoms list
7. Unintentional weight loss of more than 10 pounds (4.5 kilograms)	<a href="https://www.mayoclinic.org/symptoms/unexplained-weight-loss/basics/causes/sym-20050700">https://www.mayoclinic.org/symptoms/unexplained-weight-loss/basics/causes/sym-20050700</a> : amyloidosis not mentioned as a cause

Table 1. Continued

Symptoms mentioned: <a href="https://www.mayoclinic.org/diseases-conditions/amyloidosis/symptoms-causes/syc-20353178">https://www.mayoclinic.org/diseases-conditions/amyloidosis/symptoms-causes/syc-20353178</a>	Response in <a href="https://www.mayoclinic.org/symptoms">https://www.mayoclinic.org/symptoms</a>
8. An enlarged tongue, which sometimes looks rippled around its edge	Enlarged tongue: symptom not mentioned in the symptoms list
9. Skin changes, such as thickening or easy bruising, and purplish patches around the eyes	None of these symptoms is mentioned in the symptoms list
10. An irregular heartbeat	This symptom is not mentioned in the symptoms list
11. Difficulty swallowing	This symptom is not mentioned in the symptoms list

Of course, neither “weight loss” nor “losing weight without trying” cannot be found in symptoms list on Mayo Clinic portal. This means that also sarcoidosis and lung cancer cannot automatically be added to the differential diagnoses list searching with such wording via symptoms. In addition, when we look for “weight loss” in Mayo Clinic symptoms list (letter “W”), we obtain also misleading result: “Weight loss (See: Obesity)“. Having in mind these issues it must be explained, why Mayo Clinic does not implement systematic quality control of their information intended for broader public.

In such situation best practice would be to adhere to some standard, for instance ICD-10, R-classification<sup>10</sup>. There more than 700 hundred symptoms are presented in scrutinized manner. Focusing of the instance researched – “weight loss” – ICD-10-R uses standard wording “abnormal weight loss”. It is up to medical experts to evaluate whether the naming in Mayo Clinic portal for this instance corresponds fully to this standard symptom wording, but the final aim is to have it consistently in different parts of web site.

Here we want to mention one more deficiency of Mayo Clinic symptoms presentation. It relates to the “See also” caption, which we can see in the “Causes” table, as depicted in the Figure 3.

As we can see, amyloidosis is listed here, but among bunch of other 300 (!) different symptoms, diagnoses, laboratory tests, conditions and other medical terms. Finding “amyloidosis” on the first page of this list is pure luck, because of the starting character “A”. This list is very questionable because of the example “Acanthosis nigricus”, which has, according to its description in Mayo Clinic portal (<https://www.mayoclinic.org/diseases-conditions/acanthosis-nigricans/symptoms-causes/syc-20368983> ), only one symptom mentioned and nothing to do with “Unintentional weight loss”.



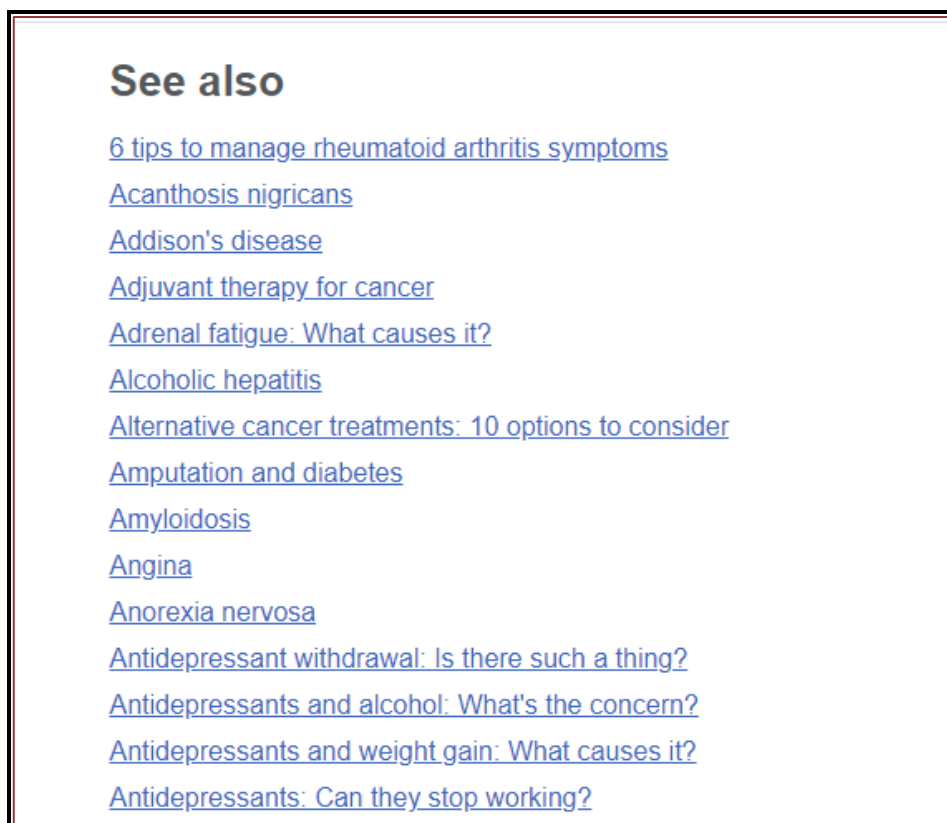


Figure 3. Caption “See also” first page in Mayo Clinic symptoms web page, from: <https://www.mayoclinic.org/symptoms/unexplained-weight-loss/basics/causes/sym-20050700> , (accessed May 2nd , 2021)

The same applies also for “angina” and majority of terms listed here. Opposite inconsistency is observed for “sarcoidosis”: despite of the fact that in the disease description “weight loss” is mentioned, in the symptom “unexpected weight loss” lists for “Causes” and “See also” this diagnosis does not appear. So, this “See also” huge and irrelevant list is actually a kind of “information noise” and can only confuse the reader.

Amyloidosis is not the only diagnosis which demonstrates inconsistency in searching it through the symptoms list. The same is observed also in the case of very common diseases, such as GERD (GastroEsophageal Reflux Disease). One of the symptoms mentioned here <https://www.mayoclinic.org/diseases-conditions/gerd/symptoms-causes/syc-20361940> is “Regurgitation of food or sour liquid”. When looking in <https://www.mayoclinic.org/symptoms/index?letter=S> , neither such symptom nor none of its keywords was mentioned in the symptoms list.

There are numerous instances of such inconsistencies in symptom/diagnosis “intersections”. As an example, the field of neurology was also examined, for common disease such as multiple sclerosis. In the disease chapter <https://www.mayoclinic.org/diseases-conditions/multiple-sclerosis/symptoms-causes/syc-20350269> the symptom “tremor” was mentioned. In the symptoms chapter, such symptom is not listed at all!? Another manifestation of inconsistency for the diagnosis “multiple sclerosis” is the symptom “dizziness”. This common symptom was mentioned in the diagnosis chapter, but in the list of diagnoses stated as the cause of this symptom, not at all: <https://www.mayoclinic.org/diseases-conditions/multiple-sclerosis/symptoms-causes/syc-20350269> .



On Mayo Clinic web site, we found also the service called „Symptom checker“: <https://www.mayoclinic.org/symptom-checker/select-symptom/itt-20009075> . Unfortunately, the content of this service is extremely poor. It consists out of only 28 different symptoms for adults, as can be seen on Figure 4. On the other hand, in general symptoms table there are some 300 different symptoms, whereas about 700 in ICD-10 (R-chapter).

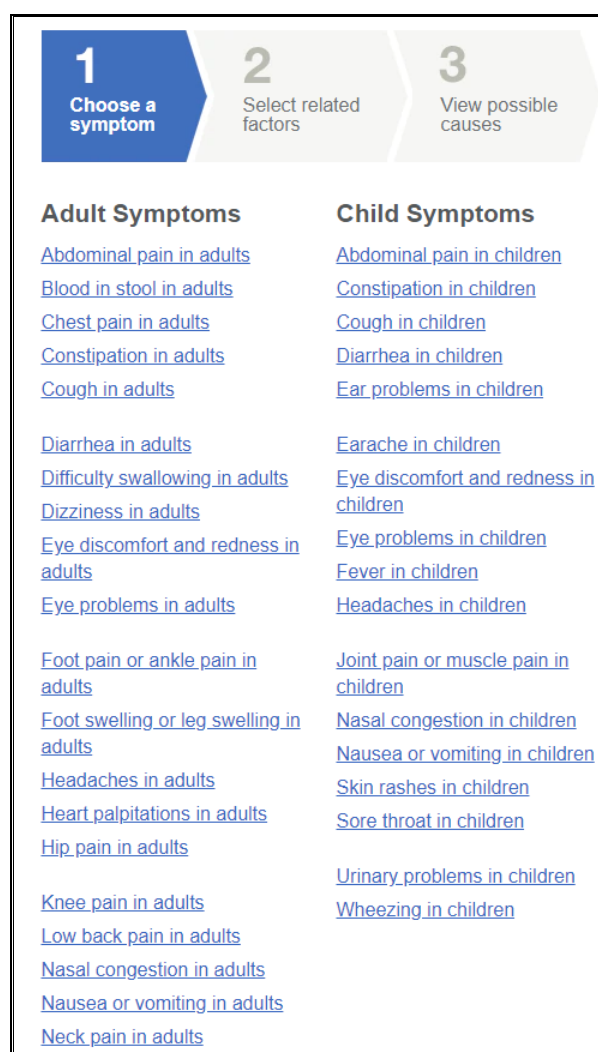


Figure 4. Screenshot of Mayo Clinic symptom checker

Similar inconsistencies were observed in another health information source – NHS. On the <https://www.nhs.uk/conditions/amyloidosis/5> web page we examined the symptom “weight loss”. In disease description, the symptom “loss of appetite” was mentioned, but when looking backwards in this symptom page, amyloidosis was not mentioned. In addition, this symptom naming is not recognized by ICD-10 at all.

On this portal similar inconsistency was observed related to “Carpal tunnel syndrome”, which was mentioned among “other symptoms” of amyloidosis. But if one goes to the symptoms page <https://www.nhs.uk/conditions/carpal-tunnel-syndrome/>, there is no mentioning of amyloidosis!

In Croatia there is also a series of internet portals dealing with health, also containing some kind of “symptoms checker” service. One of checked is <http://www.msd-prirucnici.placebo.hr>, based on the manuals of renown pharmaceutical company Merck-Sharp-Dohme (MSD).

In the Table 2. some of the symptoms listed in amyloidosis are presented.

Table 2. Symptoms list in „amyloidosis“ description (MSD), from: <http://www.msd-prirucnici.placebo.hr/msd-za-pacijente/poremecaji-prehrane-i-metabolizma/amiloidoza>, accessed May 3rd, 2021

“Amyloidosis” lists these symptoms:	Symptoms indicate amyloidosis:
1. Poor food absorption	<ul style="list-style-type: none"> <li>Poor absorption syndrome is mentioned in MSD not among the symptoms, but as a disease. A symptom of this "disease" is also “weight loss” (this "symptom" is not on the list of symptoms).</li> <li>Amyloidosis is NOT mentioned as an associated disease.</li> </ul>
2. Carpal tunnel syndrome	<ul style="list-style-type: none"> <li>Lists amyloidosis as associated disease</li> </ul>
3. Weakness	<ul style="list-style-type: none"> <li>Does not specify amyloidosis</li> </ul>
4. Abnormal sensations	<ul style="list-style-type: none"> <li>It is not mentioned as a symptom, but as a disease, it does not mention amyloidosis as a possible cause</li> </ul>
5. Increase of the spleen	<ul style="list-style-type: none"> <li>It is not cited as a symptom but as a disease, it cites properly diagnosis “amyloidosis” as possible cause</li> </ul>

In addition to the aforementioned inconsistencies, here we have a mixture of diseases and symptoms in the same list. Among five symptoms lists, only in two cases “amyloidosis” was stated in the symptom description page.

Another source examined on the issue of consistency of medical information is the one from the portal PatientsLikeMe6.

Under “amyloidosis” instance, five common symptoms are presented like the one in the Figure 5.

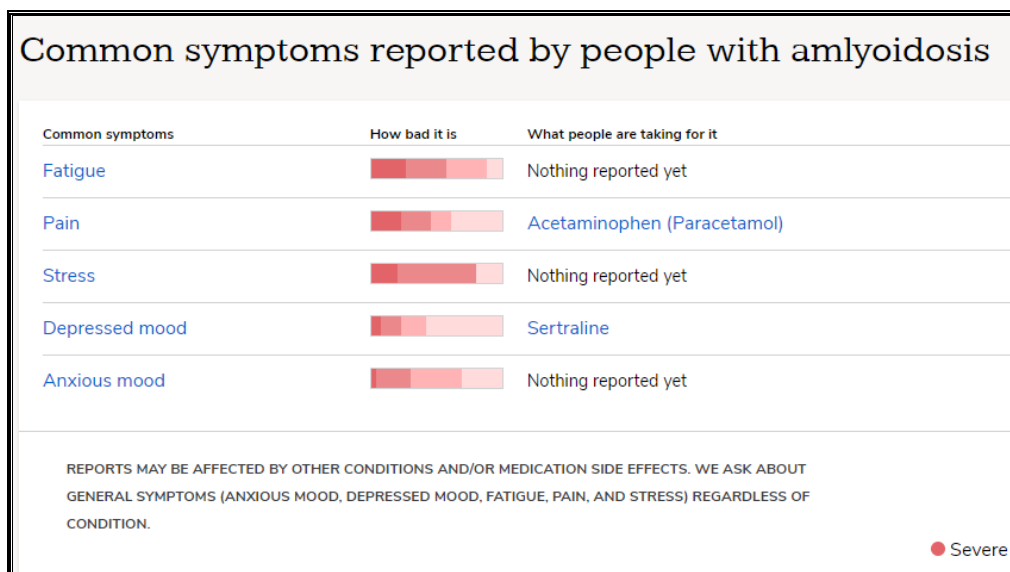


Figure 5. Symptoms’ representation in the disease page in PatientsLikeMe, <https://www.patientslikeme.com/conditions/53-amyloidosis/how-it-affects-people>, (accessed May 5th, 2021)

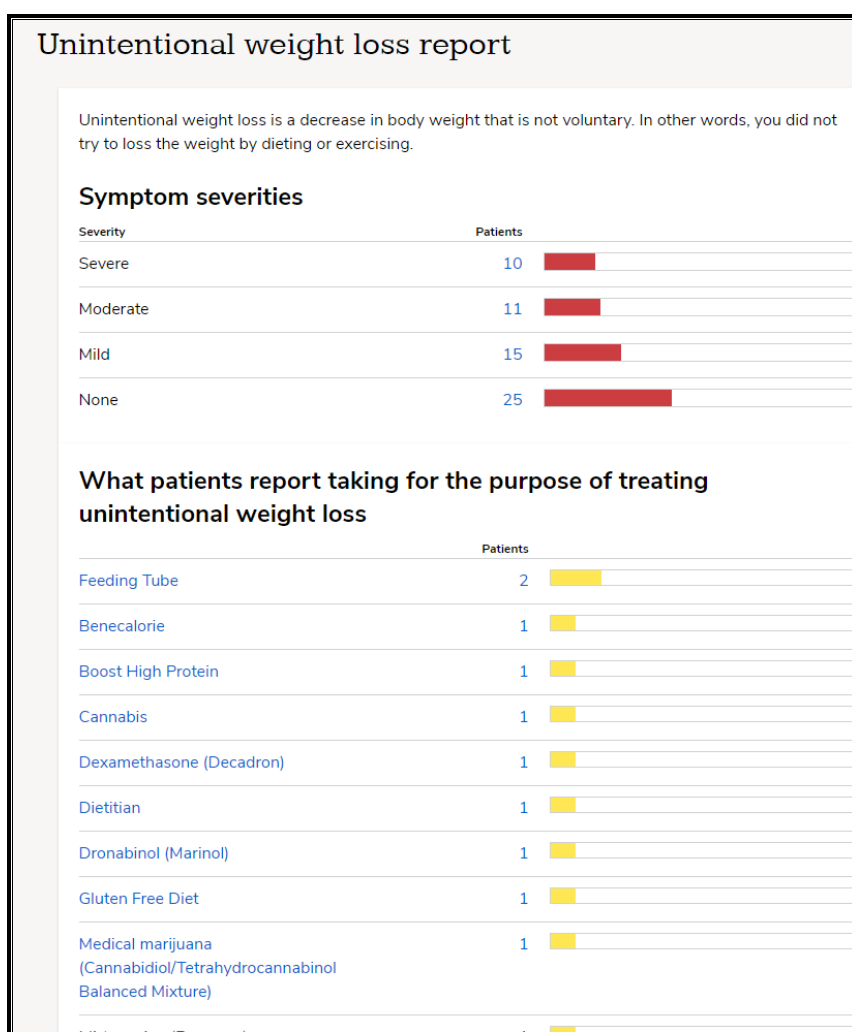


Figure 6. Symptoms' representation in the symptom page in PatientsLikeMe

Such platform with the data feed (also) from patients can be very useful for building proper database of symptom/diagnosis association. In PatientsLikeMe portal it can be implemented instead of the one depicted in the Figure 6.

Symptoms' page presented on Figure 6. in PatientsLikeMe is very questionable: it can direct the patient to take some steps by him/herself, instead to offer the information about possible causes of this symptom. This page neglects very straightforward diagnostic process, where first two steps are according to Wiki as follows:

1. Gathers all information about the patient and create a symptoms list. The list can be in writing or in the clinician's head.
2. Lists all possible causes (candidate conditions) for the symptoms.

This "list of all possible causes" or "candidate conditions" is that what we are missing in internet services researched. After two steps mentioned, prioritizing should happen and then elimination or confirmation, mostly based on laboratory tests and imaging procedures. Fifth and sixth step are finally the diagnosis and therapy.

Here on PatientsLikeMe, "middle" steps are neglected, and the patient gets information what some other patient was administered to, without association and presenting the real diagnosis!

PatientsLikeMe architecture is deficient despite the fact that this web site has complete symptoms' and diagnoses information from the patients, as shown in the Figure 7.

The screenshot displays the 'PatientsLikeMe' website interface for the symptom 'unintentional weight loss'. On the left, a sidebar titled 'Patients experiencing unintentional weight loss' lists three patient profiles: 'weaver31', 'Airpolice', and 'Wildflower\_1', each with a hexagonal profile picture. Below the list is a link to 'See all 36 patients experiencing unintentional weight loss'. The main content area is titled 'Patients with unintentional weight loss' and shows 'Showing 1 to 15 of 36 patients with unintentional weight loss'. Two patient profiles are visible: 'weaver31' (updated 4 days ago) with conditions like Parkinson's disease and esophagitis, and 'Airpolice' (updated about 2 months ago) with conditions like ALS and atrial fibrillation. Each profile includes a 'Follow' button and an email icon.

Figure 7. Symptoms' representation in the symptom page in PatientsLikeMe, <https://www.patientslikeme.com/symptoms/unintentional-weight-loss> ,(accessed May 5th , 2021)

Unlike to Mayo Clinic portal, PatientsLikeMe does not have “symptoms’ view”, which could support medical doctors in differential diagnosis list creation. This is despite the availability of such information in their database and the best practice of presenting information in a reliable way, meaning integrity and availability.

## Discussion

Author tried to get feedback about main points in this paper from the sources mentioned. Reaction is as follows:

1. Mayo Clinic: none
2. WebMD: “ We have forwarded your email to our symptom checker product team for review.“
3. MSD (Croatia): authors responded with announcing new product and cooperation interest
4. NHS: no contact available
5. PatientsLikeMe: Extensive discussion in course

In addition, several medical experts and end users representing patients were consulted concerning the issue of inconsistencies observed. Within the Croatian Society for Medical Informatics all issues discussed will be set on forum and this “round table” conclusions will be presented in separate paper.

In discussion already completed it came out that medical doctors should answer following simple bottom line question, related to the main purpose of this research:

“Is there any medical reason for mentioning a symptom in disease description and NOT to mention this very disease in this symptom’s causes list?”.

Negative answer is the evidence that this issue was worth to be researched. Positive answer must give arguments why the information about the symptom in disease web page is of some value, and the opposite is NOT!?

In answering this simple question, useful source can be found in the following (“The Diagnostic Process” (7)):

- The patient is likely the first person to consider his or her symptoms and may choose at this point to engage with the health care system....
- Typically, clinicians will consider more than one diagnostic hypothesis or possibility as an explanation of the patient's symptoms and will refine this list as further information is obtained in the diagnostic process. ...
- Limited time for clinical visits, partially attributed to payment policies (see Chapter 7), may lead to an incomplete picture of a patient's relevant history and current signs and symptoms....
- Choosing the appropriate test requires understanding the patient's history and current signs and symptoms, as well as having a sufficient suspicion or pre-test probability of a disease or condition ...

Here we see importance of symptoms’ information, delivered by the patient, considering all symptoms for building the diagnostic hypothesis. Incomplete picture is due to time limits and due to information unavailability and further diagnostic is again based on “pre-test probability”. This procedure leads us to conclusion of importance of obtaining as much as possible symptoms’ information as well as availability of complete diagnostic hypothesis list.

How the process had to be designed is described in the conclusions and recommendations caption of this paper.

## Conclusion and recommendations

There are obvious deficiencies in numerous medical portals which deal with the symptoms/diagnoses associations. These shortcomings led to the kind of “malpractice” where the tissue from biopsy was not tested with Congo red stain, targeting amyloidosis. This is somehow understandable from the point of view of pathologist, because of:

- amyloidosis is rather rare disease and
- the working diagnose was directed to the cancer.

If the list of diagnoses associated to “unintentional weight loss” would be complete, the pathologist would probably take this fact into account, after not confirming another PHD.

Therefore, all subjects responsible for medical portals in concern are strongly recommended to remove this architectural shortcoming by implementing improvements as follows:

- integral symptoms/diagnoses database must be established,
- wordings of all terms must be checked and corrected (synchronized), preferably by using some standard classification or nomenclature,
- both views should “look” at the same information source, where appropriate IT solutions are to be implemented aimed to ensure information quality and security,
- “symptoms view” has major priority to be corrected, due to its prevailing importance over “diagnosis/condition view”,
- Symptoms feed directly from patients after they get confirmed diagnose is operationally advantageous,
- all portals must establish the feedback feature where users can report deficiencies experienced and
- link between symptom and disease should be presented as quantitative measure of the “association strength” (in next improvement phase).

Of course, such long list of suggested actions should be prioritized, “low hanging fruit” principle can be considered.

In the case we analysed here, elementary information “cell” is the intersection of diagnosis and symptom. It would be of great advantage to state the strength of such association, e.g. what is the percentage of detected weight loss symptom in diagnosed amyloidosis (Table 3.).

Table 3.. Example depicting data association in table diagnosis/symptom (percentages are exemplary)

Diseases > Symptoms V	Amyloidosis
Unintentional weight loss	1,23 % / 3,21 %

In this example it is demonstrated how the strength of symptom/diagnosis association can be quantified. In this exemplary (fictional) case, the indication is as follows:

- By the onset of the symptom “unintentional weight loss”, there are 1,23 % cases with diagnosis “amyloidosis” and vice versa:
- By the diagnosis “amyloidosis”, 3,21 % patients reported the symptom “unintentional weight loss”.
- Additional measure for sensitivity and specificity can be introduced.

Of course, there is a huge work ahead to obtain these figures. Here we come again to information coding and standard medical terms wording. In digital era more and more information is entered by clicking on the screen and not by writing free text on white paper. Without intention to force medical doctors how they will enter data in patient’s medical record, other possibility is to promote standard “free text” wording, which can be posteriori analysed by algorithmic or AI based solutions. This can lead to obtaining the database with data structure, which simple model is depicted in the Table 3..

The process of gathering data and preparing information should be designed as follows:

1. MDs are asked about symptoms observed in diseases/conditions from their expertise fields
2. Previous can be supplemented with patients' personal experience
3. This data is gathered and table diseases/symptoms is formed
4. Diagnoses and symptoms have to be structured and named according to some official classification/nomenclature, preferably ICD-10
5. Both symptom's and condition's view are consistent!

This process is substantially simpler compared to the one obviously used until now, yielding correct information for all groups of stakeholders (patients, medical doctors, students).

The lack of values indicating the strength of symptom/diagnosis association should not hinder the efforts for immediate improvement of systems mentioned. Until such figures will be available, instead of percentage only some kind of "X" in the crossing cell can be checked. This is nothing new, all these data exist in Mayo Clinic portal or other medical resources on Internet. An example of such service can be seen in this prototype, developed on partial Mayo Clinic data available, screenshots in Figure 8.

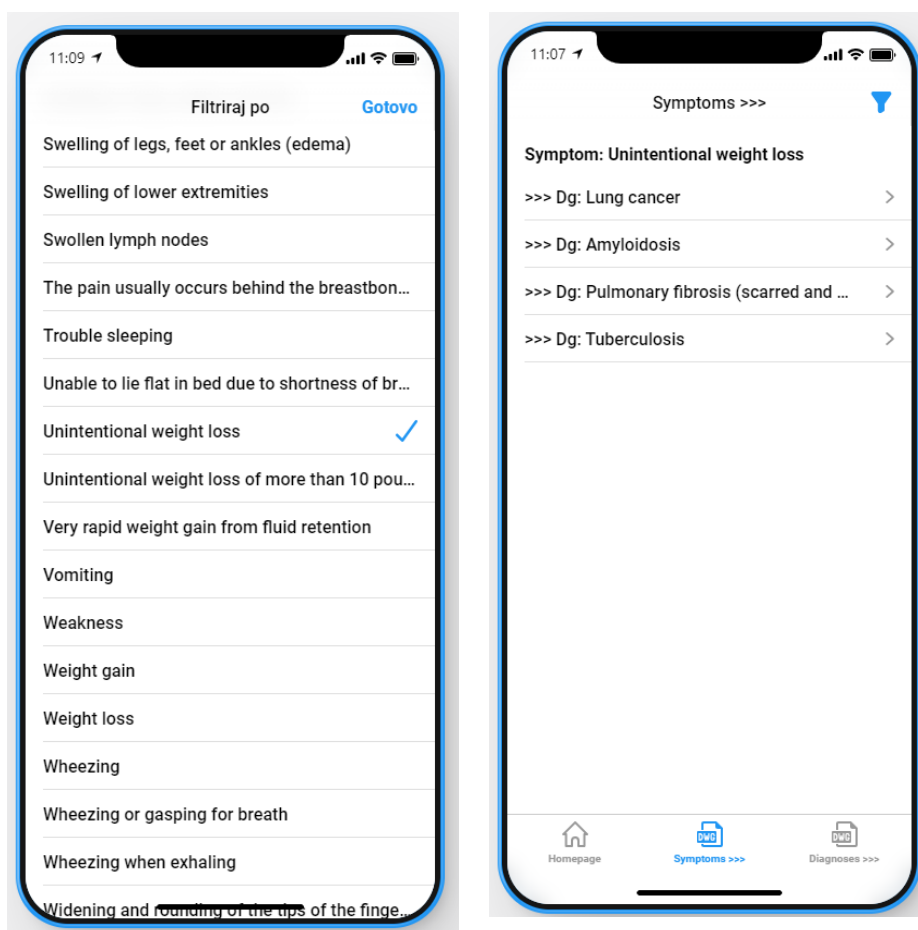


Figure 8. Author's app, Symptoms/diagnoses mapping prototype, from: <https://mayo-symptoms.glideapp.io/>, (accessed May 6th, 2021)

The following author's note has been added to the text:

- The Mayo Clinic never responded to an inquiry about this serious problem



- Mayo Clinic silently corrected the main inconsistency addressed in the article (amyloidosis and unintentional weight loss)
- Other inconsistencies mentioned have not been corrected and are still on the Mayo Clinic website, indicating that this systematic error persists
- Other mentioned sources in this paper did not respond at all to the inquiry about the same or similar inconsistencies on their pages
- Authors consulted a number of physicians regarding this inconsistency; they mostly believe that this presentation of symptom / diagnosis relationship is irrelevant in the diagnostic process.
- The patient, whose condition was the reason for this search of health portals, has mostly recovered, but due to the delay in the diagnostic process he feels lasting consequences

## References

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