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Expression of patient and caregiver uncertainty in view of decision-making in online health communities

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ABSTRACT

Objectives: On the backdrop of the current debate on shared-decision making in healthcare, we are interested in understanding how uncertainty is managed when patients and/or their caregivers resort to online health communities (OHCs) for advice regarding decisions on aspects of the disease they are not fully sure of. More specifically, we present initial results concerning the expression of uncertainty in OHCs regarding decisions that have to be made about a specific illness. Our goal is to observe how patients and/or their caregivers express uncertainty regarding information they received from specialists. This can help us understand how non-experts try to cope with information they do not fully understand.

Methods: Based on a collection of interactional data taken from two Italian OHCs, our analysis focuses on the sequences in which someone asks for advice on a certain line of action and obtains an answer. We follow a mainly qualitative approach, which includes case-based qualitative analyses. More specifically, we observe uses and functions of some lexical items (*evidentemente* (lit., evidently), *teoricamente* (lit., theoretically)) and syntactic structures (specifically clauses containing the verb *dire* (to say)) that convey a sense of uncertainty in relation to information provided by others.

Results: Our results show different types of uncertainty, providing insights into the effort non-experts make in dealing with expert knowledge and unclear situations determined by the illness and its management.

Implications for clinical practice: Our results can be used to improve healthcare professionals' training regarding their role as mediators between specialized and everyday knowledge.

1. Introduction

Literature on medical decision-making is usually focused on the consultation and considers mostly the doctor-patient dyad. In this paper, we widen our perspective on decision-making assuming that any decision is made in the context of a larger 'ecosystem', which includes all the interpersonal relations any individual is a part of. These relations – such as family, friends, acquaintances, colleagues – will inevitably influence a person's decisions, either intentionally or not. This ecosystem also includes any 'impersonal' source used to access information, such as TV, radio, Internet, social media.

Ever since its availability to the wider public, the Internet has become a favoured source of information for patients and caregivers; along with the Internet, there has been a proliferation of online health communities (OHCs). The first online community, Usenet, appeared in the early 1980s' and already contained information about health [1]. Following the development of newer technologies, new OHCs appeared that are freely accessible online. Existing studies exploring the use of online resources by patients and caregivers usually provide recommendations to clinicians on how to take into account patients' use of online information without stigmatizing it, and on how to improve the quality of online information. Many of these studies observe the impact of participation in OHCs on patients' health literacy and empowerment (among others, [2–7]).

From the point of view of the decision-making process, OHCs can be considered part of the extended ecosystem within which each individual

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is set and that influences decisions. In particular regarding health-related decisions, OHCs seem to provide large networks that individuals can turn to when they need additional information, clarifications, or simply the opportunity to express their feelings to others who are assumed to be able to understand them. Even in informal environments such as OHCs, elements of complexity in decision-making on healthcare are that decisions are made, 1) after information has been collected and considered, 2) after various options for action (if available) have been weighed out one against the other to assess which one is the most reasonable in consideration of the issue at hand [8,9], and 3) often in conditions of significant emotional distress.

Set within an ongoing line of research on decision-making in different medical settings [10–14], this paper aims to present initial results concerning the expression of uncertainty in OHCs regarding decisions that have to be made about a certain illness. More specifically, our goal is to observe how patients and/or their caregivers express uncertainty regarding information they received from specialists. This can help us understand how non-experts try to cope with information they do not fully understand.

1.1. Doubt and uncertainty in healthcare

In the healthcare context, uncertainty refers to the lack of predictability regarding healthcare outcomes in diagnoses and treatments. Uncertainty is a multidimensional phenomenon and arises from several sources and factors, including incomplete or evolving medical knowledge, variability in patient responses, and limitations in diagnostic tools [15–17] Managing healthcare uncertainty is highly relevant as it influences how decisions are made and impacts on patients' psycho-emotional well-being and satisfaction [18,19].

Research has focused on which strategies are most effective and should be used to manage uncertainty in medical interactions to prevent adverse outcomes (for a comprehensive review of the existing literature, see [20]). Mitigation and hedging strategies have been described taking into account the specificities of the healthcare context. More specifically, linguistic studies have tried to identify and assess explicit and implicit markers to figure out how patients and professionals cope with uncertainty or to understand how medical uncertainty is related to diagnostic errors and promotes/prevents shared decisions [21].

Scholars have also distinguished between a first-order uncertainty and a second-order uncertainty. In the medical context, first-order uncertainty, also referred to as probability or aleatory uncertainty, concerns "the inability to predict future outcomes" ([20], see also [17]). However, there is a second-order epistemic uncertainty related to the difficulty or inability to interpret and assess medical information's ambiguity or complexity [20]. The doubts patients express in the context of proposals made by healthcare professionals fall under this latter category: uncertainty about what to do or what will happen is often expressed as doubt about a proposal, its premises, and preconditions of acceptability [22]. In such cases, uncertainty is related to difficulty in assessing evidence because of the lack of clinical criteria or the complexity of the medical situation. Namely, uncertainty is not so much related to the probability of a given clinical outcome in these cases, but rather to the unshared common ground (Hillen, personal communication) between the non-expert patient and the expert professional.

Nevertheless, expressing doubt is a costly move: indeed, the preference for agreement in ordinary interpersonal exchanges (e.g., [23,24]) and in expert/non-expert communication (e.g., [25,26]) is well-documented. In clinical interactions, the knowledge disparity and fear of coming across as naïve or ignorant makes it harder for patients and their caregivers to express disagreement or lack of understanding; patients often prefer to soften their position using implicit and indirect linguistic markers to express uncertainty. This is why it might be interesting to analyze what happens in the case of peer-to-peer interactions in OHCs. The epistemic uncertainty that often goes unnoticed in medical interactions might emerge more explicitly when advice is asked to peers, as is the case in OHCs.

Section 2 describes the method of analysis and the corpora used for our study; Section 3 presents the results of the analysis; Section 4 is devoted to a discussion of the findings, concluding remarks, and implications of our research for the clinical practice.

2. Materials and methods

Based on a collection of interactional data taken from two Italian OHCs, our analysis focuses on the sequences in which someone asks for advice on a certain line of action and obtains an answer: from these sequences we extract and observe in particular uses and functions of lexical items and syntactic structures that convey a sense of uncertainty in relation to the information provided by specialists.

For the purpose of this analysis, data were collected using two Italian OHCs: the *Aimac forum sul tumore* (https://forumtumore.aimac.it)[1] and the *Dermaforum* (https://dermaforum.it). The Aimac association manages a website that gives access to a forum, which is public and explicitly provided as a space where anybody can contribute their experiences, emotions, information and thoughts. Dermaforum instead is a website devoted to skin diseases and disorders, which has been created by the society Myskin srl, and aims to provide a forum for doctors, patients, and anyone interested in sharing their experiences, information, and reflections on the health and well-being of the skin.

The two OHCs were analyzed by adopting a primarily qualitative approach. First, data were collected by means of the Sketch Engine software [27,28], which allows users to download the whole content of a website. A corpus of a total amount of 3,239,935 tokens (i.e. independent words) was created.[2] Secondly, the two corpora were created and automatically tokenized (i.e. each graphic form was automatically recognized by the software) and annotated for lemmas (i.e. for the basic form, or citation form, of the word) and parts of speech (i.e. for the word class, e.g. noun, verb, preposition, etc.). For the purpose of this analysis, the Sketch Engine *Word Sketch* and *Wordlist* queries were also used: the first one allows the extraction of a word's grammatical and combinatorial behavior, while the second one generates frequency lists of all parts of speech.

In order to observe how patients and/or their caregivers express uncertainty regarding information they received from specialists, we decided to look for parts of threads in which the Italian verb *dire* (to say) was used to introduce reported speech, e.g. i *medici dicono che*, 'doctors say that'. This verb is one of the most frequently used lexemes marking reported speech, i.e. used to quote what other speakers say about something (among others, [29–32]). As noted by Goodwin [33] "[i]n reported speech the voices of separate actors are found in a particular place, a complex strip of talk produced by a single speaker, albeit one quoting the talk of another".

In order to extract an appropriate number of examples of indirect speech use within the selected corpora, the Word Sketch query of the Sketch Engine software was used. This function makes it possible to extract the combinatorial profiles of a word on the basis of certain grammatical relations, i.e. the statistically most significant combinatorial relations with other words: for instance, nouns that most frequently occur in subject position can be identified, as well as those that are used as object of the verb. The verb *dire* ('to say') occurs 1294 times in the Dermacorpus (0,24 % of the whole corpus) and 14,591 times in the Aimac corpus (0,46 % of the whole corpus).

Within these exchanges, we then conducted more in-depth, case based analysis on the uses of adverbs *evidentemente* (lit. 'evidently') and

[1] Aimac forum on cancer. 'Aimac' is an acronym for 'Associazione italiana malati di cancro, parenti e amici' (Italian association of cancer patients, relatives and friends).

[2] In particular, the corpus is composed of 2,761,612 tokens of the Aimac subcorpus and of 478,323 of the Dermaforum corpus.

teoricamente (lit. 'theoretically, in theory'). These two adverbs in particular were chosen following an inductive approach to the data: while reading the exchanges in which participants asked and provided advice in relation to recommendations from specialists, we noticed that the adverbs emerged as indicators of two different kinds of inferences in discussions where participants were trying to make sense of the information they had received from clinicians, or that they were reading in the medical reports. As has been argued, speakers use these adverbs as mitigators in the sense that they serve to avoid overbearing or unfounded statements [34,35]; more specifically the adverbs *evidentemente* and *teoricamente* also carry epistemic or evidential meaning, serving to signal speakers' state of knowledge or speakers' information source. In the literature on epistemic and evidential linguistic structures, however, they are not reported as indicators of uncertainty: hence our interest and decision to further explore their uses qualitatively.

The analysis was conducted manually, by examining the extended contexts of a selection of conversation threads and identifying:

i) What kind of information is attributed to doctors, and how this information is 'used' by the participants in the thread.
ii) What kind of information is labeled through the adverb *evidentemente* as being based on evidence, and on what kind of evidence; and what kind of information is labeled through the adverb *teoricamente* as being mere hypothesis.

Data were grouped according to the subclasses that were identified by means of the inductive analysis. The sequences were evaluated by three researchers responsible for the study design, who independently interpreted the words in their contexts of use. Whenever an uncertain case emerged, it was solved through discussion.

The results of the analysis are presented in the following section.

3. Results

The different interactions give rise to a number of requests for information coming from caregivers or patients. Requests are addressed to other non-expert participants who share (or have shared) a similar experience of the disease/illness. Answers are given by non-experts, on the basis of their personal experiential knowledge.

In the following subsections we show single turns from interactions that involve three different participants:

i) The specialist (D-doctor): is absent and does not take part in the interaction (i.e. the doctor who provided the diagnosis mentioned by someone else).
ii) The Patient-User (PU): someone who is personally involved in the disease and uses the OHC to ask for information; PU is the user who asks for advice or opinion.
iii) The Interlocutor-User (IU): someone who answers PU's questions by asking for other pieces of information, giving opinions and making suggestions.

3.1. What doctors say

In both corpora, the noun *medico* 'physician' and *dottore* 'doctor', and nouns referring to healthcare specialists (e.g. *dermatologo* 'dermatologist', *oncologo* 'oncologist') emerge as the most frequent subjects of the verb *dire*. Tables 1 and 2 are obtained by means of the Word Sketch query of the Sketch Engine software and show collocations of *dire*, ranked by typicality scores (calculated by means of the LogDice index[3]). The tables show the raw frequency of the collocation in light blue and the LogDice score in blue. The higher the collocational value (blue column to the right), the stronger the collocation, that is to say the attraction between the term and the verb.

Some examples from the original posts, showing the context in which

Table 1
Wordsketch results of *dire* in the Aimac corpus.

Subjects of *dire* ('to say/tell')		
medico ('medical doctor')	258	11.5
medici dicono ('medical doctors say')		
oncologo ('oncologist')	143	10.9
oncologo dice ('oncologist says')		
dottore ('doctor')	85	10.3
dottori dicono ('doctors say')		
oncologa ('oncologist')	46	9.5
oncologa ci ha detto ('oncologist told us')		
Chirurgo ('surgeon')	37	9.2
chirurgo mi ha detto ('surgeon told me')		
dottoressa ('doctor')	34	9.1
dottoressa ha detto ('doctor said')		
urologo ('urologist')	32	9.0
urologo mi ha detto ('urologist told me')		
mamma ('mum')	41	8.8
mamma ha detto ('mum said')		
cosa ('what')	34	8.6
cosa dire ('what to say')		
giorno ('day')	28	8.4
giorno mi ha detto ('day said to me')		
volta ('once')	24	8.3
volta ho detto ('once I said')		

Table 2
Wordsketch results of *dire* in the Dermacorpus.

Subjects of *dire* ('to say/tell')		
dermatologo ('dermatologist')	105	12.2
dermatologo *mi ha detto che* ('dermatologist told me that')		
medico ('medical doctor')	40	11.6
medico mi ha detto che ('medical doctor told me that')		
dermatologa ('dermatologist')	29	11.2
dermatologa mi ha detto che ('dermatologist told me that')		
dottore ('doctor')	20	10.5
dottore mi ha detto che ('doctors say')		
vuoi ('you want')	13	10.4
vuoi dire che ('you mean that', lit. 'you want to say that')		
dottoressa ('doctor')	7	9.5
dottoressa mi disse ('doctor told me')		
derma ('derma[tologist]')	5	9.0
il derma mi ha detto ('derma told me')		
ginecologa ('gynecologist')	3	8.3
mia ginecologa dice che (my ginecologist says that')		
ginecologo ('gynecologist')	3	8.3
ginecologo mi ha detto di sostituire Gracial ('gynecologist told me to replace the Gracial')		

[3] The *LogDice* statistic measure is used to identify co-occurrence patterns, i.e. the occurrence of two or more items together. This measure is used in Sketch Engine to identify collocations and its typicality; it is based on the frequency of occurrence of the base word (the node) and the collocate, as well as on the frequency of co-occurrence of node and collocate. What is important is that "logDice is not affected by the size of the corpus and, therefore, can be used to compare scores between different corpora" (https://www.sketchengine.eu/my_keywords/logdice/).

the verb *dire* is used to report specialists' opinions or suggestions[4]:

(1) il mio dermatologo dice che durerà sei mesi
My dermatologist says it will last for six months
(2) Dopo un mese sono andato a rifare le analisi e *il dottore mi ha detto* che la cura stava facendo il suo effetto
After a month, I went for re-testing and *the doctor told me* that the treatment was having effect
(3) *Il medico diceva* che la reazione è normale perché tutte le tossine venivano buttate fuori dagli organi compromessi
The doctor said the reaction was normal because all the toxins were being flushed out of the compromised organs
(4) Ultima cosa Dottore se posso… *Il dermatologo mi ha detto* di assumerlo a stomaco pieno, sempre alla stessa ora
Last thing Doctor if I may… *The dermatologist told me* to take it on a full stomach, always at the same time

Beyond reported speech, other uses of the verb *dire* are attested in OHCs, in which *dire*-structures show several functions that point to various degrees of uncertainty related to what doctors have said or might say. In the following sections, we describe these different functions by reporting examples from the corpora and by showing what kind of information is attributed to doctors, and how this information is 'used' by the participants in the thread.

3.1.1. Uncertainty of Interlocutor-User about what Patient-User says

IU asks for information about the specialist's previous opinion; these types of sequences highlight a double assumption: i) that IU takes it for granted that PU has spoken to the doctor, and ii) considers the doctor's opinion important for the diagnosis and possible treatment.

Examples:

(5) Ciao Stefania, ma *i medici cosa dicono*? Finché ti propongono opzioni c'è speranza … anche io ho letto tutto e di più ma non serve a nulla se non a farci ancora più male
Hi Stefania, but *what do the doctors say*? As long as you are offered options there is hope … I have read everything and more, but it does not help us and it hurts us even more
(6) Cara Jeffry come si sa ogni caso è a se, poi sembra che nessuno per quanto riguarda la tua cara mamma parli di hospice, ma *cosa ti dicono i medici a riguardo*? Nel nostro caso specifico la situazione ha avuto un crollo talmente repentino, che immagino nemmeno loro se lo aspettassero. […] I medici spero ti aiutino a capire cosa doverti aspettare.
Dear Jeffry as you know each case is different, then it seems that no one talks about hospice regarding your dear mother, but *what do the doctors say about it*? In our case the situation had such a sudden collapse, I imagine that even they were not expecting it… […] I hope the doctors will help you understand what to expect.

In such uses, *dire* appears in questions inquiring about the recommendation made by the doctor.

3.1.2. Uncertainty of patient-user about what doctor said

PUs do not completely believe what the doctor said and turn to others when searching for information about the object of their uncertainty (in the following example, the patient information leaflet for prescribed drugs):

(7) Salve sono maschio di 54 anni. Ho in passato assunto Minocin per acne cistica, ora non ottenendo piu' effetto mi e' stato prescritto isoriac (iniziati oggi 11/01 cura 20 Mg /die con tutti gli esami di rito eseguiti) Due curiosita': *dermatologo e medico m'hanno detto di* evitare l'alcool (io bevo solo qualche birra con la pizza, non di piu') ma non trovo questo avviso nelle istruzioni del farmaco e poi secondo voi dopo quanti gg. mediamente (in larga ipotesi ovviamente) potrei cominciare a sentire secchezza della pelle? in futuro postero' eventuali progressi o regressi Distinti saluti
Hello, I am a 54-year-old male. I have previously taken Minocin for cystic acne, since it is no longer having any effects I was prescribed isoriac (started today 11/01 treatment 20 Mg /die with all the usual exams performed) Two questions: *dermatologist and doctor told me to* avoid alcohol (I only drink beer with pizza, nothing more) but I don't find this warning in the drug instructions; and, also, in your opinion after how many days on average (broadly speaking of course) might my skin begin to feel dry?

In this case PU is doubtful about what specialists have told him, thus he turns to the OHC for additional opinions about similar or more complete indications given by Doctors to inform the decision he has to make.

3.1.3. Uncertainty of Patient-User triggering Interlocutor-User's distrust

Doubts of PU generally concern the outcome of therapy and the prognosis. In this case the uncertainty of PU is contrasted with the "certainty" of IU based not on scientific expertise or evidence, but on a lack of trust in specialists.

(8) Ciao minul si mamma era in casa abbiamo deciso così…lo so è difficile ma sta soffrendo da morire magari tu lo vedi bene ma in realtà soffre da morire perché lui già a capito tutto […] mi dispiace moltissimo…stagli vicino *nn dare retta hai medici che ti dicono 2 settimane - 2 mesi so medici mica Gesù*
Hello minul yes my mom was at home we decided this way…I know it's hard but he is suffering to death maybe you see him alright but actually he's suffering to death because he already understood everything […] I'm terribly sorry…stay close to him, *don't listen to doctors who tell you 2 weeks - 2 months, they are doctors, not Jesus*
(9) Guarda Valerino mi spiace per te ma qualsiasi cosa tu faccia devi morire perchè comunque di tumore si muore Tu mi potresti rispondere ma guarda gli oncologi mi hanno detto e poi la scienza dice che …… E io ti rispondo: "La scienza, i medici? *Non devi mai credere a quello che dicono i medici sono tutte bugie*. Tu potresti rispondere: " però gli esami confermano che adesso sto bene" e io ti direi " Gli esami? qualsiasi esame tu faccia non serve per il cancro"
Look Valerino I am sorry for you but whatever you do you will die because anyway from tumor we die You could answer "but look the oncologists told me and then the science says that"…… And I will answer: "Science, doctors?" *You must never trust what doctors say it's all lies*. You could answer: " but medical tests show I am good now" and I would say "The medical tests? Whatever test you do it doesn't help with cancer"'

In these cases, Doctors' opinions are totally contradicted by IU, who, instead of directing the PU to another specialist, suggests that he/she disregard the doctor's opinion.

3.2. Uncertainty adverbs involving evidence and theory

With Fraser [36] we can consider the adverbs *evidentemente* and *teoricamente* as pragmatic markers and specifically commentary markers in the light of their function of a) signaling aspects of the message the speaker wishes to convey and b) specifically signaling a speaker's comment on the basic message [36]. More specifically, since

[4] Extracts from the original posts in Italian are followed by their English translations. The words relevant for our analysis are signaled in italics.

evidentemente and *teoricamente* signal a comment on either speaker's state of knowledge or speaker's information source, contributing to signal certainty or uncertainty of the speaker, they are good candidates to be considered when dealing with linguistic ways in which uncertainty is expressed.

By using the Keyword query function in SketchEngine, which calculates the raw frequency of occurrence of different parts of speech, we observed that *evidentemente* and *teoricamente* did not occur among the most frequently used adverbs in either corpus. Regarding the adverbs with epistemic function, some are used to emphasize the true value of something (e.g. *veramente* 'truly', *davvero* 'truly'), others convey uncertainty, such as *forse* 'maybe', *probabilmente* 'probably', *presumibilmente* 'presumably'.

We elaborate further on *evidentemente* 'evidently' and *teoricamente* 'theoretically', because, although in the literature on epistemic and evidential linguistic structures they are not reported as indicators of uncertainty, in our data they appear also in this function.

3.2.1. *Evidentemente*

The adverb *evidentemente* shows peculiar uses which deserve further investigation. Even though the adverb has a low frequency of occurrence in the corpus, its semantic values are relevant to our analysis since they are extremely distant from the original meaning of the adverb. According to the GRADIT Dictionary of Italian [37], *evidentemente* means: i) in an evident manner, or ii) without any doubt. These values are not completely expressed by the instances collected in our corpora, as Table 3 clearly shows.

As shown in the table, the meaning of 'evident manner' is rarely attested, and that of 'without any doubt' is not present at all. Indeed, the corpus analysis reveals that this adverb may play the role of a marker of inference introducing hypotheses regarding the assessment of circumstances or of other people's actions. The following extracts exemplify this function:

(10) Prima però TAC di controllo. *Evidentemente* credono che si possa controllare/risolvere davvero
First, however, follow up CT. *Evidently* they believe that you can really control/resolve it

(11) Piuttosto la Rm che hai fatto, evidenzia la lesione, ma ha dubbi sulla ECE ovvero l'estensione extraprostatica della neoplasia, *evidentemente* tale neoplasia è a ridosso della capsula e quindi le immagini fanno sospettare un probabile sconfinamento
Rather, the MRI you have done shows the lesion, but has doubts about the ECE or extraprostatic extension of the neoplasm, *evidently* this neoplasm is close to the adrenal gland and therefore the images make one suspect a probable encroachment

(12) Ovviamente ogni caso è a se, ogni tumore è a se per cui *evidentemente* mia mamma rientrava nelle casistiche "standard"
Obviously, each case is unique, each tumor is unique, so *evidently* my mother fell within the "standard" cases

(13) *Evidentemente* in un primo memento, complice lo shock di quanto avvenuto, hai tenuto il dolore "confinato" in un angolino
Evidently at first, due to the shock of what happened, you kept the pain 'confined' to a corner

(14) per fortuna non mi sono fatta male, ma è stata colpa mia e mi sto chiedendo se è il caso che io cacci il naso fuori di casa, visto che *evidentemente* "sto mollando"
Luckily I didn't get hurt, but it was my fault and I'm wondering if I should stick my nose out of the house, since I'm *evidently* "giving up"

In these examples the adverb marks an assertion as a tentative explanation for a circumstance. So, for example, in case (10) "evidentemente" marks "credono che si possa controllare/risolvere davvero" as a hypothesis on the medical team's behavior that explains the reason for a follow up CT scan. The explanation introduced by the use of the adverb refers to a fact – typically clinicians' actions or decisions – and it expresses uncertainty regarding its assessment. A similar behavior can be observed in the uses of *teoricamente*.

3.2.2. *Teoricamente*

Generally speaking, the adverb *teoricamente* is used to refer to theory and theoretical reasoning, such as in the example (15), taken from our corpus.

(15) solo noi ammalati sappiamo cosa ci sentiamo lo proviamo sulla nostra pelle. loro lo sanno solo *teoricamente*
only we sick people know what we feel we experience it directly. they only know it *theoretically*

However, it is worth noting that a majority of uses of this adverb does not concern theory at all, but is related to other functions, as Table 4 shows.

On the one hand, this adverb plays the pragmatic role of a mitigator [38], downplaying the assertive force as in the following examples:

(16) Gli studi dicono che almeno *teoricamente* che Lexgeva sia un pochino migliore dello zometa ne avete parlato tu e il dottore?
Studies say that at least *theoretically* Lexgeva is a little better than zometa, did you and the doctor talk about this?

On the other hand, *teoricamente* is used to express uncertainty of the speaker, in uses similar to the ones observed for *evidentemente*:

(17) Può riprendere anche sul pancreas? *Teoricamente* sì
Can it also pick up on the pancreas? *Theoretically* yes

(18) Questa mattina gli hanno tolto il catetere, domani *teoricamente* lo dimetteranno
This morning they removed his catheter, tomorrow *theoretically* they will discharge him

While in the first case (17) we observe a pure conjecture, in the second one (18) the speaker puts forward an explanation for the decision of the doctors (removing the catheter) but, as in the cases with *evidentemente*, marks it as uncertain.

Table 3
Quantitative analysis of *evidentemente*.

evidentemente	Aimac corpus	Dermaforum	TOTAL
a. 'in an evident manner'	5 (7 %)	2 (40 %)	7
b. 'without any doubt'	-	-	-
c. Uncertainty: 'marker of inference - others'opinion'	42 (60 %)	3 (60 %)	45
d. Uncertainty: 'speaker's hypothesis'	23 (33 %)	1 (20 %)	24
TOTAL	70	5	**75**

Table 4
Quantitative *results* of *teoricamente*.

teoricamente	Aimac corpus	Dermaforum	**TOTAL**
a. Literal value	3 (18 %)	6 (8 %)	9
b. Other values	14 (82 %)	68 (92 %)	82
TOTAL	17	74	**91**

4. Discussion and conclusion

4.1. Discussion

In this paper we have presented a study on the expression of uncertainty in relation to recommendations or information provided by specialists to patients/caregivers. We have analyzed a collection of interactional data taken from two Italian OHCs, focusing on the turns in which someone asks for advice regarding 'what the doctors said about something'. As for uncertainty itself, we have considered what in the literature is described as second-order epistemic uncertainty, i.e. the one related to the difficulty or inability to interpret and assess medical information's ambiguity or complexity. In such cases, uncertainty is related to difficulty in assessing evidence because of the lack of clinical criteria or the complexity of the medical situation [20].

The examples commented on in Sections 3.1.1, 3.1.2, and 3.1.3 show that uncertainty is expressed by actors who play different roles in the dialogues that develop within OHCs. Specialists are talked about (in our corpus they do not appear so much as active users) and what is uncertain seems to be the trust that can be granted (or not) to them.

As for the analysis of the adverbs *evidentemente* and *teoricamente*, it allows us to observe different types of uncertainty. In some cases, the two adverbs are used in similar ways to mark the fact that something is to be understood as a tentative explanation. Our examples are cases of, so to say, 'backwards reasoning' that tries to explain or assess events in the light of the apparently strongest available evidence: it is a kind of defeasible reasoning that could be proven wrong if stronger evidence were to appear, in the form of scientific explanations, new evidence, etc. In other cases, the adverb *teoricamente* was used to mark the expression of conjectures or as a mitigator of assertive force.

5. Conclusion

Considerations of counterfactuals and possible future situations, reasoning in the face of unclear evidence, and conjectures are different expressions of uncertainty that might not appear as clearly in dialogues with specialists. Indeed, the main function of OHCs seems to be that of offering an environment in which patients/caregivers can try to manage the uncertainty deriving from not knowing or not understanding facts or advice they encountered during medical encounters. The sequences of conversation threads we have analyzed can also be considered in some cases as efforts to 'build' new knowledge by combining expert knowledge and individual experience. This can be considered a first step towards larger and more detailed studies on different kinds of uncertainty, as they are expressed in peer-to-peer encounters.

5.1. Practice implications

The results of our study can contribute insights as to how patients and caregivers deal with information or recommendations they do not fully understand. This kind of understanding would certainly be useful in order to manage hesitancy or non compliance also in the patient-provider encounter. Indeed, it seems that patients and caregivers do not look for advice online mainly because they distrust the specialists. Based on our (limited) findings, it would seem useful for clinicians not to demonize the use of the Internet or of OHCs, but rather to provide their patients and caregivers with the necessary criteria to recognize credible advice.

As shown by the examples discussed in Section 3.1.3, the doubts patients and caregivers develop in relation to therapeutic suggestions or to diagnosis can be met in peer-to-peer interactions with deeply rooted distrust in specialists. It would appear that building relational competences that support the construction of trusting and open relationships between specialists, patients and caregivers would be the best way to counterbalance the potentially negative effects of such strongly antagonistic replies.

CRediT authorship contribution statement

Bigi Sarah: Conceptualization, Supervision, Writing – original draft. **Ganfi Vittorio:** Formal analysis, Methodology, Resources, Writing – review & editing. **Parlato Sibilla:** Formal analysis, Resources, Writing – review & editing. **Piunno Valentina:** Formal analysis, Methodology, Resources, Writing – review & editing. **Rossi Maria Grazia:** Conceptualization, Writing – review & editing.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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