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Caregivers' Reasoning about Oncological Treatment in Online Discussions

A comparative analysis

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ABSTRACT: In long-term conditions, a great burden is placed on caregivers, who contribute to decisions regarding treatment. Studies on caregivers' role in the decision-making process are scarce. In this paper, we aim to describe reasoning patterns on decisions regarding treatment, as they appear in two corpora consisting of discussions posted on online fora that include patients, caregivers and professionals. In the analysis, we focus in particular on the argument schemes used by caregivers.

KEYWORDS: argument schemes, caregivers, decision-making, medical argumentation, oncology, online health communities

1. INTRODUCTION

This paper is set within an ongoing line of research that aims to explore the reasoning used for decision-making in different medical settings (Bigi, 2016; Lamiani et al., 2017; Bigi, 2018; Macagno & Bigi, 2020; Macagno & Bigi, 2021). 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, and should be considered. The ecosystem also includes any 'impersonal' source used to access information, such as TV, radio, Internet, social media. An additional element of complexity in decision-making is the fact that decisions are made after 1) information has been collected and considered and 2) various options for action (if available) have been weighed one against the other to assess which one is the most reasonable in consideration of the issue at hand (Elwyn & Miron-Shatz, 2010; Walton, Toniolo & Norman, 2014).

In this paper, we take into consideration both these levels of complexity by examining how the caregivers of oncological patients collect and assess information in online health communities (OHC). In particular, we are interested in how reasoning about the management of oncological conditions is developed in OHC. As Holmes (2019, p. 5) states: "More studies are recommended to explore the resources available to people living

with and beyond cancer and identify how people evaluate and make decisions based on Internet use."

The paper is structured as follows: section 2 explains the structure of decision-making in a dialogical and argumentative perspective and expands on how the 'relational ecosystem' works with respect to decision-making and online health communities. Section 3 presents the study design and results. Section 4 discusses the results and offers concluding remarks.

2. MAKING DECISIONS ABOUT HEALTH

The imperative of patient participation and the ethical limitations posed to healthcare professionals ever since the end of World War II have favoured the development of studies on how health-related decisions are made. The most relevant line of research produced in this perspective has been the one on 'shared decision-making', a concept that has been subjected to serious reconsideration in recent years (Kaldjian, 2017; Duffin & Sarangi, 2018; Gerwing & Gulbrandsen, 2019; Dingwall & Pilnick, 2020; Elwyn et al., 2023; Pieterse et al., 2023). A different approach has taken models developed in the field of argumentation studies and applied them to decision-making in healthcare (Akkermans et al., 2023; Jackson, 2020; Bigi, 2018; Rubinelli, 2013; Pilgram, 2012). In this study, we follow the latter 'trend' and refer in particular to the model in Figure 1, proposed by Walton, Toniolo and Norman (2014), which represents graphically the structure of a deliberation process understood as the combination of different 'dialogue types'. This figure is useful for our discussion to understand the close connection between the information that can be collected regarding an issue and the proposals that can be formulated in order to make a decision on the most appropriate course of action.

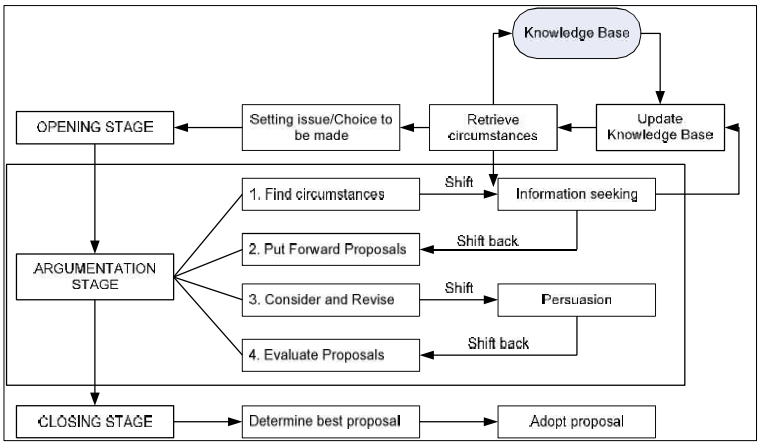

Fig. 1 – The model of the deliberation dialogue (Walton, Toniolo & Norman, 2014)

In the specific case of decisions regarding health, the oncological context poses specific challenges because of the nature of the disease. What frequently happens is that patients are supported by family members, partners or friends, who are usually referred to as 'caregivers' and who are carrying a great emotional and sometimes also physical burden (Kirk, Kabdebo & Whitehead, 2022; Alam, Hannon & Zimmermann, 2020). Relevant for

our study is that they are also often crucially involved in the process of making decisions regarding treatment (Acquati et al., 2022; van Oosterhout et al., 2021; Gieseler et al., 2021). In the oncological setting, especially in cases of advanced cancer, it can be quite challenging to decide for a particular kind of treatment because it is difficult to find a balance between the goal of 'length of life' (LoL) and 'quality of life' (QoL), which are not always aligned (Shrestha et al., 2019). It is at these points that decisions stop being the result of a discussion between the doctor-patient dyad and become the outputs of wider deliberation processes, involving many participants. Indeed, once the options for treatment have been explained and discussed in the doctor's office, there is usually time to consider and come back with a decision. Studies show that this time is often used by caregivers to collect additional information, second opinions or more generically moral support in view of making the decision (with or on behalf of the patient) (Verma et al., 2022; Dionne-Odom et al., 2019; Kinnane & Milne, 2010). In consideration of these factors, it makes sense to characterize the interactions that occur at this stage in the decision-making process as instances of "polylogue", as described by Kerbrat-Orecchioni (2004). Referring to the representation in Figure 1, this polylogical phase corresponds to point 1. in the Argumentation Stage, where participants have the goal to define circumstances and find relevant information that will help them decide. In the case of OHCs, this phase is realized through 'wide' interactions that involve multiple participants, not necessarily acquainted with each other, but bound together by the common experience of the disease. During these interactions, participants do not only seek and provide information, but also support it through argumentation in order to frame it as reliable.

Ever since its availability to the larger public, the Internet has become a favoured source of information for patients and caregivers, and along with the Internet, also online health communities, which have existed for about forty years now, and recently have increased the numbers of their users, also due to the development of social media (Jackson, 2023). 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 to OHCs on patients' health literacy and empowerment (among others, Watson, 2018; Holmes, 2019; Braun et al., 2019; Zhou & Wang, 2020; Johansson et al., 2021; Chi et al., 2022).

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

The reason to consider caregivers' use of OHC to retrieve information about treatment is that it is not completely clear how discussions in online communities might influence patients' and their caregivers' decision-making regarding treatment (Holmes, 2019).

3. STUDY DESIGN AND RESULTS

Our first step in this exploration has been an analysis of reasoning patterns, as they appear in two corpora, one in Italian and one in Russian, consisting of discussions posted on online fora that include patients, caregivers and professionals.

We identified two freely accessible online health communities: "AIMAC forum" (https://forumtumore.aimac.it/) and "Rak pobedim" ("we will defeat cancer", http://www.rakpobedim.ru/forum/). The first one, which we will refer to as AF, has been created by an Italian association that includes oncological patients, their caregivers and friends. The second one, which we will indicate as RP, is a similar online health community, occasionally including healthcare professionals.

In our analysis, we first searched for threads about treatments. To do this, we considered the titles of threads and the titles of conversations within threads. We then singled out from each forum a sample of 20 conversations regarding treatments, experience about treatments, and how to manage them. We analyzed the kind of questions posed by caregivers, in order to better understand what kind of information they were seeking and how they asked for it. Finally, we considered the answers by forum members to describe the kind of information provided and, if possible, the argument schemes (Walton 2006) used by participants to support their recommendations and make them more credible.

The next section reports the main results with examples from both fora. The original posts in Italian and Russian have been translated by the authors (SP for Italian cases, and VN for Russian cases).

3.1 Results

The first step in our analysis consisted in the observation of caregivers' questions. Comparing both OHCs, it is possible to notice some similarities in this respect. When posing questions that have to do with treatments, caregivers tend to ask for: real-life experiences regarding treatments that have been prescribed; second opinions; advice and help regarding cases in which not even the clinicians seem to be able to find solutions.
Table 1 offers examples of these different kinds of questions.

FORUM	EXAMPLES
RP	(1) Immunotherapy. Dendritic cell-based vaccine. Hello. I need feedback from real people who have experienced this vaccine themselves. What are the results? Is it worth the risk? (2) Good afternoon, please advise me. My mom has been diagnosed with second stage breast cancer. Chemotherapy is prescribed before surgery. Are there any more modern methods of treatment that are not so harmful to the body? (3) Hello. Does anyone have any feedback on recently invented viruses? Any side effects or contraindications? I know this is, let's say, unofficial, but I'd like to try it. My husband got bone metastasis, middle ear squamous cell cancer. Doctors are already letting him go home.

AF	(4) I am turning to your association for advice about the right therapy to follow after surgery, also in consideration of your experience. (5) My father was diagnosed with stage IV glioblastoma. If you can tell me, according to your knowledge, I ask about the best center in Italy to rely on. (6) Does anyone have any knowledge/experience of a specialized center that can help for one last (desperate and different) attempt?

Table 1. Caregivers' questions.

Many of these questions allow us to detect a recurrent dilemma that seems to concern caregivers in their decision-making about treatments, i.e., the uncertainty of the outcomes. In other words, it is often the case that patients have been prescribed a certain treatment or have been proposed an alternative, but it is not at all obvious if the proposed therapy will be beneficial, or – in the case of an alternative – which of the different suggestions could be the most appropriate. It seems that in all these cases the decision has been left to patients and their caregivers, thus the need to seek advice where someone could have already experienced the same situation. Table 2 shows examples of these cases.

FORUM	EXAMPLES
RP	(7) My mother, 77, relapsed after having a kidney removed. Her condition is now tolerable. We have Sorafenib (generic) but we are afraid to take it. We are afraid that the side effects will cause her to give it up after a week or a month, and then the tumor might grow more dynamically - this is a concern, although I haven't read this about Sorafenib specifically... (8) My mom had her uterus removed and a biopsy revealed cancer cells. […] Now the doctor suggests doing a course of radiation and remove lymph nodes, just in case! If I agree with radiation, is it necessary to remove the lymph nodes so urgently? […] Mom is 59, active, NOT an old woman. I would not want to worsen her health.
AF	(9) Q: I am really afraid that this treatment will be too strong for him and that he will be very sick… is there someone who knows it and can tell me what they think? A: if in your dad's case chemotherapy has been suggested, it means that it makes sense. It's terribly hard to weigh costs and benefits of different therapies, but personally I would focus on the quality of life rather than on mere duration (10) Last week he started chemotherapy and he will have to undergo another 3 cycles + radiotherapy, then he will be operated and he will resume the chemotherapy cycle. What should I expect? Could he live a normal life after the surgery? Will this heal him?

Table 2. Requests for advice.

Based on these and other examples, it seems possible to say that caregivers' questions tend to point to two main reasoning patterns (Table 3).

In the first one, a certain treatment has been prescribed and this is the reason for seeking a kind of 'second opinion' with the peer group in the OHC. The implicit premises in this line of reasoning are that: 1) the group may have relevant information, and 2) experts may have a general picture (e.g., through statistics), but peers have the experience (and may know about exceptions).

The second line of reasoning usually follows from the fact that no treatment is considered possible and this is the reason for seeking advice about 'alternative' treatment options. The implicit premises in this case are that1) the group may have relevant information, and 2) it is possible that there exist 'non institutional' options that experts will not consider and that the group might be aware of.

FORUM	EXAMPLES
RP	(11) Good evening, I need advice and recommendations... my dad has stage 4 prostate cancer. Since August 2014, every 3 months we have been injecting Zoladex, and every day we drink Bicalutamide and Omnic. […] Some days ago he began to complain of pain in his legs, his face became yellow, he is experiencing shortness of breath. […] A paid oncologist recommended to cancel Bicalutamide completely and to check his heart. I don't understand why his heart, as I always associated the yellowing of the skin with a liver problem. Maybe someone has experienced something similar...? I will be grateful for any little information and advice! (12) What do you think about treating cancer with fractional asd 2[1]? Why I ask: a friend of mine has cured her husband from lung cancer for 5 years. Now he is healthy. My mother started too, so far without result, though only a month has passed.
AF	(13) We would like to ask for some advice on the therapy he is following, as about 10 days ago he had the first epileptic seizure and until now they still have not found an antiepileptic drug that works, they are trying with Vimpat. (14) Is there anyone who made use of these "tonics"??? Or anyone who has pain problems for which oxycodone does not help, and has found alternatives?

Table 3. Examples for the two different lines of reasoning used by patients' caregivers.

As for users' replies, they are usually based on their personal experience, and advice is supported by arguments from example. Table 4 shows a few cases.

FORUM	EXAMPLES
RP	(15) Hyperthermia is one of the most effective treatments for cancer. A good acquaintance of mine was refused everywhere, but the Hyperthermia Institute accepted him and carried out the procedures. The result is that he has lived for 10 years and feels like a healthy man, even his metastases have gone away.

[1] Refers to a drug that is not explicitly proposed for the treatment of cancer.

	(16) At the last, 4th stage, if treated ONLY with immunovaccine and nothing else, then no, it is not worth it. [...] When my wife was diagnosed with 4th degree oncology, the immuno-oncologist refused to treat her. He's a great specialist and doctor. But he's not omnipotent. And he can only cure early stages with immunovaccine.
AF	(17) Hi Irene, it's difficult to provide certainty but I think this behavior is due to the illness, not to treatments. My dad had the same kind of tumor… (18) Palliative care does not mean "imminent" end of life. For personal experience with mom, during the first months and the following months of care we had home care that provided nurse, doctor and psychologist who occasionally visited my mom and treated postsurgical wounds etc...

Table 4. Replies containing arguments from example.

Other times users back up their advice by referring to its source, e.g. the family doctor, the pharmacist, or a reliable research center/hospital. In these cases, they are still providing their personal experience or opinion, but they make its acceptability stronger by calling into play those institutional 'actors' that in some cases are not considered sufficient by those who ask the questions. This kind of 'backup' is never contested.
Table 5 shows one example for each forum of this kind of reply.

FORUM	EXAMPLES
RP	(19) Hello, the Petrov NIC in St. Petersburg produces their own vaccine based on dendritic cells, as I understand it is a state institution, a research centre... why is it rubbish?
AF	(20) Very dry eyes, for example, it looks like they can be prevented with blueberry supplements, my pharmacist told me!

Table 5. Replies containing arguments from authority.

4. DISCUSSION AND CONCLUSION

Based on our analysis, some considerations can be proposed for discussion.

First of all, albeit having been shown in previous studies from a clinical and psychological perspective, the relevance of analysing caregivers' participation in the decision-making process emerges also from our study through a very interesting linguistic phenomenon. In both corpora, it is possible to observe a peculiar use of the first-person-plural pronoun 'we' by caregivers when reporting about treatments. Indeed, this pronoun, employed in its inclusive sense (Fillmore, 1971) as shown in the examples in Table 6, displays the attitude of the caregivers to participate in, or even carry, the burden of the treatment, as if they were suffering the negative effects of the disease *in the same way* as the patients. This specific use of the inclusive pronoun 'we' can be considered as an example of empathetic deixis, which highlights the emotional proximity and solidarity, or even identification, of the speaker with the situation and the person they are referring to

(Lyons, 1977; Andorno, 2005). In this regard, Graneva (2022, pp. 180-181) talks about the "psychological we", pointing out that in Russian this kind of empathetic deixis, which expresses the speaker's empathy towards the referent, is very frequent in mothers' narratives referred to their children: *My načali (= on načal) v 4 mesjaca kušat' risovuju kašku* [We started (= he started) eating rice porridge at 4 months]. Table 6 reports examples of this phenomenon.

FORUM	EXAMPLES
RP	(21) Hello! We have been diagnosed with recurrent lung cancer with an EGFR mutation in exon 19. We have been treated with gefitinib for almost 3 months. Once a month we have blood tests. (22) We started getting HIFU and (we) had chemo at the same time.
AF	(23) Testicle tumor should be an easy one, so most doctors say... right, but ours unfortunately is aggressive! (24) In January we'll be using the wheelchair, and we'll start chemotherapy.

Table 6. Examples of empathetic deixis in caregivers' posts.

A second consideration has to do with the fact that patients and caregivers access OHCs when faced with the dilemma of having to choose between treatments that are likely to increase the length of life (LoL) at the expense of its quality and treatments that may guarantee a better quality of life (QoL) but a shorter survival. The dilemma is created by the fact that this choice is often accompanied by uncertainty: experts may have said that "in most cases" either LoL or QoL are to be expected as the effect of treatments, but it may not always happen that way. Thus, any decision involves a high degree of risk and seeking help in OHCs is part of the deliberation process implied by such dilemmas. Indeed, before any decision it is necessary to collect at least the relevant information. In cases such as the ones observed in the OHCs we analysed, users are looking for the kind of information that experts cannot provide, i.e. personal experience.

Indeed, the first generalization from our data regards the kind of information that participants share. We observe three kinds of information, or knowledge, that are sometimes competing and other times 'collaborating': professional expertise, personal experience, and 'alternative' knowledge.

Professional expertise is what participants have been provided with by their healthcare professionals. It is expressed through protocols, guidelines, assessment criteria and statistics deriving from randomized controlled trials. This kind of expertise is what constitutes the starting point for accessing the forum: it is either not enough (doctors are not able to recommend anything), not satisfactory (recommendations for treatment do not guarantee positive outcomes), or users simply want to double check the information they have. In all of these cases, the other members of the OHC are considered to be knowledgeable 'actors', potentially able to fill the gaps left open by experts.

Indeed, personal experience is what OHCs are concerned with. This is the second kind of information that is shared by participants; actually, it seems to be precisely the kind of information most participants are looking for. In most cases, it looks like personal experience is considered complementary to professional expertise, not because the latter is

unreliable or in bad faith, but because members of the OHC may have experienced those rare symptoms or effects that statistics are not able to capture. In reply to requests for advice (e.g., "what should I do?", "what would you do?", "is there anybody who went through the same experience and can advise me?"), participants back up their advice by using their own experience as arguments from example; in these cases, the use of empathetic deixis strengthens the arguments by making caregivers appear as though they were primary sources of the information. However, differently from what happens in many public controversies about health issues (Jackson, 2020), this anecdotal evidence is not used to push aside professional experience or to contradict it.

In this respect, it is interesting to observe what happens when some participants ask about or try to suggest 'alternative' solutions, i.e. non-scientifically grounded advice of some kind. In many cases their posts are simply dropped by the others, in some cases rather heated discussions are triggered precisely by the fact that such suggestions are unreliable and not backed up by sufficient evidence.

Clearly our data is too limited to make relevant generalizations regarding the different role of these kinds of knowledge in the decision-making process, but it is interesting to note that in both fora the majority of participants displays a trusting attitude towards science. By seeking advice and help on OHCs they are not showing disregard or lack of trust in scientific knowledge, but are trying to 'fill the gaps' that that kind of knowledge is leaving open. Our observations are also in line with the findings reported in Macagno and Bigi (2021) where different levels of evidence were described and their uses measured in a corpus of doctor-patient consultations. In this corpus, experts tended to look for recurrent patterns in patients' symptoms, and used this evidence to support their advice; patients, on the other hand, tended to use evidence coming from direct observations and to use it without making any interpretative effort. In a sense, this is what happens also in our OHCs, where evidence from direct observations is used to support the advice users are giving each other.

Other considerations can be relevant at a more general level. More precisely, in spite of its limitations this analysis offers the opportunity to observe how the acceptability of certain arguments may change depending on the conversational context in which they are used (Walton, 1996; 1998). Indeed, arguments from example such as the ones commonly used by participants to support their advice would never be considered acceptable if used by healthcare professionals. On the other hand, arguments from authority or expert opinion that would probably be considered signs of a paternalistic approach used by professionals are frequently used to back up participants' advice to each other.

This paper reports on an ongoing line of research on deliberations regarding health. Within this ongoing effort, a continuation of this exploration will include the analysis of the expression of doubt and 'expertise', to describe how the reliability of the answers is established. At another level, we intend to analyze, where possible, the causes of doubt: apart from what we have already observed, are there other reasons why people ask for advice on OHCs? Why were the interactions with experts not enough? Finally, which arguments are not considered acceptable by members of OHCs? Through these and other research questions, we aim at reaching a more comprehensive description of the deliberative processes that lead to decisions about health.

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