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Rare Cancers and Digital Quest for Authority during Covid 19 Pandemic

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ABSTRACT

In the unprecedented context of the pandemic and its communicational corollaries, the “infodemic” and fake news, this paper aims to investigate the search for online information and support for rare cancer patients and their families. By mobilizing the tools of content and discourse analysis, we question the construction of the expert parent figure, in online forums, focusing on a very specific type of cancer: glioblastoma. It is a rare brain cancer more than often diagnosed at a late stage, with a very poor prognosis and huge and disabling neurological impairments at the time of identification of the disease therefore the analysis conducted focuses on the words of the patients’ families. To what extent has this diagnosis and the difficulties in accessing information been modified by the ongoing pandemic since 2020? The treatment of information in times of pandemic produces communicative emphasis to the detriment of certain pathologies; in the same way that the hospital crisis required the sorting of patients accessing the intensive care units. The comparative analysis of a double corpus, before and during the pandemic, will allow us to address the possible transformations of the enunciations of authority online. When a web patient chat room happens to deal with glioblastoma, the discussion occurs most of the time between close relatives. Therefore, this paper deals with the following questions: how do these discourses show the parents’ building of authority? To what extent is their on-line quest for authority also a try to free themselves from the medical ≪already-said≫, by requesting a kind of ≪never-said≫? Through the semio-communicational analysis of a specific corpus of web forums, the paper underlines how parents position themselves relatively to other actors and how they produce their own ≪authorization process≫. The study conducted here aims to understand how, in the case of glioblastoma, the mediation of digital writing can promote the position of authority and the recognition of the parent as a potential expert in this disease characterized by its rarity. It is within the restrictive online discourses frameworks that impose their “order of discourse” that truly “compensatory” information is deployed insofar as it fills what is felt to be a void, especially during the pandemic. This information is a construction cobbled together by families for families in the inter-discourse of the forms of digital dialogism specific to forums, a double escape that underlines the inadequacies of legitimate words and fundamentally questions the question of authority when authority itself seems to lack knowledge.

Keywords: Social media, Patient/parent expertise, Rare cancer

INTRODUCTION

In the unprecedented context of the pandemic and its communicational corollaries, the “infodemic” and fake news, this paper aims to investigate the search for online information and support for rare cancer patients and their families, in the broader field of ≪health democracy≫.

The concept of “health democracy” has been institutionalized in France since 2003 by the law on “patients rights and the quality of the health system”. It defines the participation of users in the functioning of the health system and puts forward the notions of “accreditation of associations and training of users’ representatives”. The 2016 law on the “modernization of our health system” confirms health democracy by increasing the place of health system users in regional and national bodies; it also specifies their rights (information on costs, health data, etc.).

The “expert patient” appears in this context and, while it raises questions, the notion is put forward by the institutions, which define it as the patient who has acquired solid knowledge of his or her disease over time, thanks in particular to therapeutic education. He or she does not replace the caregiver, but promotes dialogue between medical teams and patients, facilitates the expression of other patients and contributes to improving the understanding of the discourse of healthcare teams.

This notion of the “expert patient” is particularly explored by the human and social sciences team of Siric CURAMUS, from a philosophical, sociological, anthropological and communication point of view. Indeed, the rarity and poor prognosis of some of the cancers concerned by three medical programs lead to complex limits. It is one of these limits that we propose to explore in this contribution, based on the case of glioblastoma, a rare neurological cancer that is little known to the general public, which, at the time of diagnosis, is often very advanced with a poor prognosis and already disabling neurological damage. As a result, glioblastoma is a cancer for which there is little information on the web and, when it is discussed in digital “patient forums”, it is almost always a relative, a parent who speaks.

Therefore, this paper deals with the following questions: how do these discourses show the parents’ building of authority? To what extent is their on-line quest for authority also a try to free themselves from the medical ≪already-said≫, by requesting a kind of ≪never-said≫? To what extent has this diagnosis and the difficulties in accessing information been modified by the ongoing pandemic since 2020?

The treatment of information in times of pandemic produces communicative emphasis to the detriment of certain pathologies; in the same way that the hospital crisis required, in France, the sorting of patients accessing the intensive care units. The comparative analysis of a double corpus, before and during the pandemic, will allow us to address the possible transformations of the enunciations of authority online.

The analysis of the digital public space of glioblastoma, due to the great specificity and rarity of this disease, allows us to consider a kind of magnifying glass effect on the construction of authority and/or authorities online. The way in which the different categories of actors, institutional, medical, professional, commercial, associative, patients and their families appear in the digital public space of glioblastoma will allow a micro-approach of the construction, distribution, negotiation of positions and discourses of authority. Moreover, a precise work on the main patient forums, in fact forums of parents or relatives, will allow to enter in the detail of the narratives and discourses of authorities. We will see how the participants position themselves in relation to the actors already mentioned and how some of them come to produce themselves formulations of authority which are based on an expertise linked to lived experience and related by the privileged form of testimony. At this point, as Oger states, "the 'authorial function' joins authority as a way of defining and regulating a field of exchange and discussion, more than controlling the statements produced in their wake" (Oger 2013: 112).

Corpus

Through a semio-communicational analysis of a specific corpus of web forums, this paper underlines how parents position themselves relative to other actors and how they produce their own ≪authorization process≫.

The first digital landscape of glioblastoma sketched by the search made on the Google engine is quite classical in the sense that "public information is integrated into socio-economic logics". We find the public sector, the institutionalized and more restricted associative sector, commercial sites (the pharmaceutical laboratory) and health information sites that can be described as "nebulous third parties" (Akrich and Méadel 2010).

This is confirmed with the results of the query with the group of terms "glioblastoma forum" which allowed us to gather 28 results including eight results related to the testimony; the sites hosting these discussion forums are Allodocteurs (a site linked to the health and medicine television programs of France 5), Santé médecine Journal des Femmes (a health-related website linked to the Journal des Femmes, an online media production created in 2003), Forum-doctissimo (the leading French site, in terms of audience, dedicated to health and well-being), Guérir du cancer (a site initiated by a French oncologist promoting a "metabolic treatment"), Forumcancer. ch (Swiss site moderated by the Ligue Info Cancer, Swiss Cancer League), Forum ligue-cancer.net (site of the Ligue contre le cancer already presented), Beauté Test (beauty shopping guide created in 2010) and Carenity (social network for people concerned by a chronic disease created in 2011). The variety of sites hosting these forums allows to go from universes open to very large audiences or towards more restricted circles.

The systematically collected exchanges bring together 89 enunciators/authors of singular texts (a single post) or recurring texts (participation in online conversations). This corpus was then analyzed by means of a semio-communicative approach using thematic content analysis, discourse analysis, pragmatic and narrative analysis, and sociosemiotics. It is based on the implementation of a "plasticity" or methodological creativity because each new reflection implies the implementation of different combinations. The analysis grid constructed *ad hoc* is based on the following main categories: the main theme or themes addressed in the contribution: the factual aspects (dates, places, treatments, etc.), the qualifications of relations (in the context of the contribution), the social and cultural aspects (in the context of the contribution), the qualifications of relations (in the family, with the outside world, with the carers, between the participants in the forum), the qualifications of feelings, the discursive clutch, the modalization, the uses of the imperative and its equivalents, the qualifications of the sick parent and his or her relation to the illness, explicit discourses of experience sharing, advice and/or expertise and, last but not least, the impact of the pandemic on these previous items.

The study conducted here aims to understand how, in the case of glioblastoma, the mediation of digital writing can promote the position of authority and the recognition of the parent as a potential expert in this disease characterized by its rarity.

RELATIONSHIP TO KNOWLEDGE(S): THE INADEQUACIES OF THE "ALREADY SAID"

The architexts of the forums constitute a first authoritarian manifestation because they prescribe to speakers constrained possibilities of digital expression (Jeanne-Perrier 2006). In this way, the texts of the parents or patients take the form of fragments of different sizes which, when placed in series, form a "diatext" (Fournout 2009) on the screen. This diatext is characterized by its twofold intertextual dimension: the first ties each of the individual texts to those of the other participants; the second, shared, opens up to the evocation of speeches held, heard and collected "outside" the forum. This second type of intertextuality, which we call "already-said", constitutes the heart of the analysis carried out in this first movement, aiming to grasp the relationship maintained by the speakers to the knowledge(s) on glioblastoma carried by different potential incarnations of the medical authority and to understand how this relationship legitimizes this authority but also highlights some of its fragilities.

Relation to Medical Figures

"Patients who express themselves on the Internet are very concerned about respecting the sharing of roles and not encroaching on the doctor's prerogatives," noted Akrich and Méadel (2010: 45). This is also true in the case studied here: neither the patients nor their parents question the presumed authority of medical knowledge and the person who embodies it. On the contrary, the way in which the figure of the doctor is evoked in a transversal way fully participates in the construction of his authority. This figure thus appears as a reference in the online exchanges.

The doctor is often present on the analyzed online forums beyond a tutelary figure; in fact, in the forums of The League or the Journal des Femmes, a doctor is part of the moderators of the discussion. This helps to prevent the advice given from going astray and, above all, to refer the parent to the doctors who treat the relative suffering from glioblastoma, reminding them of the sometimes very unusual evolution of this type of cancerous tumor. The presence is the same before and during the pandemic. The latter is not mentioned by the interactants, whether they are laymen or doctors. The exchanges around the figure of the MD are completely stable.

Therefore, we have chosen to extend the corpus to social networks, which are more sensitive to the interpenetration of news. The aim is to understand if this first impression of stability of the exchanges, to the point that it seems that Covid is not addressed, is the same on platforms like Facebook or Instagram. We therefore followed the online exchanges of the French Facebook group "Glioblastoma Grade 4 - Échange, Partage, Soutien, Espoir" and the results on Instagram of #glioblastome. While the Facebook account centralizes the same type of exchange as the asynchronous online forums, what is gathered on Instagram is somewhat different. However, the results about medical teams are the same, without evolution during the pandemic. Instagram often pictures scientists, doctors and surgeons in their activity, for example, picturing a woman in a white coat in front of a bench carrying medical equipment and a screen or staging a surgeon seen from behind while operating on the brain of a patient in a technically top of the art operating theatre.

Even more, the figure of the doctor is "referred to" when it is evoked as a generic category. "There is a great surgeon who can do something," Henri advises Yany about her husband's illness, while Ultra-Marine replies to the same speaker that "this type of tumor needs to be treated by very specialized neurosurgeons. More than a given person, the reference targets and legitimizes the medical institution as a whole, through the caregiver. This confidence is also reflected in speeches that refer to the entire field of medical research: "Let's hope that science will advance and will be able to cure this one!" exclaims Olf 393.

Strengthened by this interweaving of scales - discipline, institution, person - in which it is perceived and mentioned as a reference, the medical figure is indeed reinforced as a "de facto "authority in the forums analyzed (Lamy 2017: 43).

Expression of a Lack of Information

Antoine Spire and Rollon Poinsot refer to the potential "conspiracy of silence" felt by patients, which "envelops the announcement to the point of suffocating it, generating suffering for all" (2007: 163). In the case of the forums studied, there is indeed suffering expressed with regard to an informational "silence"; however, it is not perceived as a conspiracy, a term that implies intentionality, but rather as a shared powerlessness in the face of the opacity that surrounds this rare disease.

"My dad has had glioblastoma since 2012. (…) If his treatment stops, unfortunately we can't know how long he has left. It could be a few days, a few weeks, a few months", writes Maud before closing her account with an anaphoric repetition of the same regret: "We can't know". The fact that the patients' parents are aware of this powerlessness, which is shared by the doctors, may explain the absence of reproaches towards them and the unanimous understanding of the comments made about them.

The analysis of the exchanges on forums as well as on the Facebook group and #glioblastoma on Instagram shows, once again, the great stability of the discourses and the themes; the difficulty to understand the disease, to find information remains the same and it is first of all for this reason that the newcomers connect. The violence and urgency of glioblastoma, whose rapid evolution makes information intake chaotic and crucial relegates to nothing the other pathologies. The Covid 19 pandemic seems to be absent from this universe where patients and caregivers are as if in apnea, in an isolating bubble linked to glioblastoma. The rest of the world, even a unique pandemic in recent history, does not manage to break this "entresoi", which is undoubtedly necessary to face the stages of glioblastoma. There is no room for anything else.

This impossibility of knowing, linked to the rarity of the disease, is also attributed by the writers to the poverty of institutional and media discourse likely to explain it. Laure recounts the quest for information that she undertook following the announcement of her father's illness: "With my family, we scoured the oncology department in search of discussion groups on this cancer, in vain. Yes, nothing exists in the province for affected patients, we don't talk about this cancer, because it is not sold, because the prognosis is poor."

"The sources of information on the Internet on this disease are few and particularly distressing on the possibilities of remission especially since the cases of recurrence seem to be numerous", regrets for its part Espoir 04. On the Facebook group, the search for information is recurrent for patients and especially for relatives who have not received enough information or who want to understand the "cutting edge" remarks that accompanied the announcement of the diagnosis: "For medicine, he is already dead, except that it is out of the question that we stay there with our arms hanging down waiting for his time to come because the medicine "does not know how to do it" or "the words that were used are "non operable", "chemo" during 5 months then MRI of control then Xrays...I discover this word "glioblastoma" tonight, I read dark things ...So rather than feeding myself with information from approximate sources, being a novice and completely lost, I refer to you."

The Call for Testimonies to Fill in the Gaps or Medical Discourse

The questions thus formulated find their extension in a complementary dimension commonly shared on the forums: the call to fill the lack of information by testimonial accounts that will institute the personal experience in a form of knowledge. In addition to the sometimes desperate search for information, there is a request addressed to the other participants that already builds, a priori, their legitimacy to be able to say. The statement of this request takes two forms which can coexist or which, in any case, are not exclusive of each other. The first one is related to the crossing of the disease itself.

"I am especially apprehensive about what will happen next because I understand that we rarely recover from it. I would like to have your testimonies for those who are going through or have gone through it...", says

Marineke. The questions can also be more specific and directly target the treatment modalities experienced by the participants or their parents. “I would like to know if anyone has been treated with DEPATUX for recurrent stage 4 glioblastoma,” asked Cris. On the Facbook group, a few people ask about possible problems: “What happens if a patient on temodal 5/28 gets the flu and or Covid? Will the treatments be stopped?”

Finally, and this is the second main form of request, the speakers question and wonder about the conduct of daily life during the illness and about the very personal register of relationships to be maintained with one’s loved ones throughout this experience. “What should I do with my boyfriend? I can’t afford to be selfish and let him stay by my side, [...] what is the wisest decision to make, you who have already been through this; who have survived this damned disease!”, implores Imp26jc.

Alice Krieg-Planque characterizes discourses of authority as “discourses whose linearity has been worked on in such a way that neither the unforeseen nor the overflowing find any place in them” (2015: 115). The medical authority figure is in no way called into question here. On the other hand, its discourse is shaken by the limits and shortcomings expressed by the forum participants. The “déjà-dit” - whether medical, institutional or media - thus proves insufficient in the face of the magnitude of the upheaval experienced.

It is precisely this insufficiency that will lead the speakers to seek out discursive outbursts, which will move away from the classic formats of medical authority to produce others that are of the order of the “never-said” and allow access to the symbolic exchange evoked by Baudrillard. In L’Échange symbolique et la mort, he exposes the aberrant and inadmissible demand of the sick (and dying) to base an exchange on this difference - not at all to be treated and rectified, but to give his illness, and that it be received, therefore symbolically recognized and exchanged, instead of being neutralized in the technical hospital death and in that strictly functional survival which is called healing and health (1976 : 299). The vagaries of dealing with emergencies as Covid are sometimes mentioned by a few participants in the Facebook group, whether it is because an appointment is moved, a hospitalized loved one catches Covid as a nosocomial illness. The question of vaccination of patients also arises, sometimes causing violent reactions from relatives who perceive the fight against Covid as an indecent demand on a relative who is already in a coma.

RELATIONSHIP TO EXPERIENCE, CONQUEST AND NORMALIZATION OF A “NEVER-SAID”

Faced with the complexity and rarity, even relative, of the pathology, glioblastoma patients and especially those accompanying them, are therefore confronted with a poor and technical “already-said”, difficult to find and to evaluate, even though it undoubtedly benefits from the medical authority. The research that leads parents to patient forums is a quest for the similar, the comparable, that is to say the narration of the experience of others in order to gather in the testimonies “unpublished” elements since they have never been said by the authorities already known (Jolivet 2010). The experience, of which the testimony essentially gives an account, opens the door to the constitution of a “said in common” which allows the construction of the between-said, to constitute it into a discourse circulating by recurrence. The convergence, the resonance creates a reproducibility of the discourse of experience and contributes to normalize it to bring it to a sufficient degree of authorization.

At the same time, it is an authority and a link that emerges from the sharing made possible by the digital devices known as “forums”. The creation of a link through remote devices is found in so-called therapeutic education devices, which rely in particular on regular calls between caregivers and patients. Being able to tell and exchange about the experience of the disease is part of their major benefits (Mayère 2018). Indeed, beyond the attention, it is a link that is established and documented, through what therapeutic education describes as a “continuity built by nurses through their records in patient files” and, in patient forums, through the open archive that is the history of exchanges (Marcoccia 2004).

The participants’ awareness of this archiving is part of the first authoritative placement of these discourses. What they write, their experience, will remain and can be consulted by others who find themselves or will find themselves facing the same questions, months or years later. When the pathology is rare and the information is scarce and difficult to reach and collect, as is the case for glioblastoma, we witness a setting at work of parents and sometimes patients whose effects are very different from those of therapeutic education; the scriptors of the forums, while disciplining themselves, give themselves the means to feel more in action (Mayère 2018).

The exchange and pooling of experiences allow parents to build a “lay expertise” that moves from a so-called weak expertise, “that is to say, the appropriation of expert knowledge”, to a lay expertise in the strong sense - that is, “a knowledge of the layman as a layman” (Broca and Koster 2011: 112). The scriptors contribute to the writing of a never-said made necessary as much as legitimate by the technicality of the caregivers’ discourse (see above). The reason for the announcement of the diagnosis present in most of the first interventions in an online forum is, at the same time, in most cases, what justifies speaking online. The announcement transforms the discursive roles and places, from this event some become patients and others parents (Berthelot-Guiet and Charbonneaux 2020).

In February 2022, in response to an express and somewhat desperate request for advice from a patient’s relative whose drug treatment must be temporarily suspended, about 25 contributors replied in a short, precise manner, testifying to their knowledge of the disease, the treatments and the hazards: “I am down to 74,000, Chemotherapy was postponed until I was at 100,000, Nothing serious, Don’t worry,” “MRI hasn’t moved from October. Avastin every month.” Nevertheless, it was the same before Covid 19.

From there, another authority can be built, not competing with that of the doctors, but necessary against the brutally transformed daily functioning. This authority comes from the customs when that of the doctors comes from the source (Romeyer 2008). The very form of the testimony, as it is encouraged or even prescribed by/on the forums, becomes a lever for authorization for the parent, manifesting another authority that takes its source in the experience of the illness. The testimonies build a knowledge shared by the patients' families that concerns the illness, the treatments, the experiences, the emotions... A distribution of knowledge is unfolded, between "the knowers", namely the caregivers, and a new category, in the process of being produced, of "the knowers", namely "those whose knowledge has been acquired in action, through the lived knowledge transmitted, but also conquered in response to a question, to a particular personal problem" (Méadel 2010: 111).

This knowledge is certainly profane but, through the digital forum, the exchange of experiences and their aggregation, it produces an expertise and represents an authority. Thanks to these forums, parents and patients move from the status of "those who do not know" to the status of those "who have knowledge and points of view that can be as established, as well-founded, as rational, as useful as those of scientists" (Epstein, Méadel 2010: 112). And this, especially since the forum ensures the dissemination, archiving and constitution of a database.

The notion of lay expertise as experiential expertise (Akrich and Rabeharisoa 2012) emerges in our corpus, as evidenced by Laureteste's message: "Less than a year ago I didn't know about this disease, now that it has taken my Dad, I would like to make it known to the general public and your program could allow that. However, I think that it should not be approached only from the "medical" point of view but also show the collateral damage of such a disease (repercussions on the family, the daily life decreased...)".

We are indeed faced with a demand for a narrative that is coupled with a collective setting. The collectivization of experiences and their narratives allows for a sufficiently strong distancing to lead to the production of explicitly expert messages, ranging from the classic form of advice to that of injunction, or even exhortation. The "advice" covers several aspects (Mayère 2018). First, they may concern the work directly related to the illness. The exchanges show a strong acquisition of the ability to speak technically about the symptoms, evolutions and treatments related to glioblastoma and even to state opinions and recommendations, as in the message from Ks1000 : "I wouldn't even advise avastin. The end will be the same anyway and the side effects of avastin are worse than the glioma...".

The "advice" also addresses daily work with the disease, which refers to "the activities required of each person to ensure the necessities of daily life, while taking into account the implications related to the disease" (Mayère 2018: 205). Injunctions, norms are stated by scripting parents (Tourette-Turgis 2013) to accompany others, as Ultra-marine does in response to Yani: "It's true that remembering the happy moments, those that made the history of your couple, what unites you, is important. (...) Any small joy is good to take, any word of love good to say and to hear".The advice and encouragement don't change over the years and the Covid 19 pandemic is into the scope: "Take good care of your dad. You are doing the best and that's the most important thing!" or "I would just say enjoy every day month or year.... good luck to you and your family..."

Finally, biographical work is of great importance to maintain self-awareness and self-esteem (Mayère 2018). Indeed, the struggle parallel to that of the caregivers carried out by the parents is articulated, for the latter, with a strong investment in the field of daily care and accompaniment and the emotions they engage. The hyper-daily life stated by the parents is also composed of "digital affects," understood as "an ability to feel or experience emotions" (George and Julliard 2018). In the case of glioblastoma, parents become subject-actors of the disease through the very act of signifying emotions about it. The expression of emotions comes from their authorization through the forum system. The testimony as a discourse of authority of the experience enters the general system of the web that builds the credibility of the participants and produces an "authority of the deserving" (Candel and Gkouskou-Giannakou 2017) as stated in Lou's message to Thyli: "bravo for the effort you are making for your dad good luck and a lot of patience".

In their exchanges, parents produce individual biographies close to the exemplum, insofar as, through micro-narratives, obligatory "narrative detours," they make it possible to engage the discourse and produce a singularized and singularizing narrative that is articulated to a collective value through the creation of a kind of repertoire common to the participants (Abiven 2016). The exemplum, the individual biography enters the collective narrative first because the individual, serialized in a microform, becomes collective and allows one to move toward exemplarity for others and for society. The biographies make possible a "monumental act" drawn up by the scripting parent for his or her sick parent, "the act that makes people recognize" (Barthes 2009). Secondly, because this micro-narrative treatment extends from the patient to his or her family, which is also idealized, the figure of the combatant is extended to them, as in And31ku's response to Luna67110 : ≪He feels that we still need him because my whole family, my mother and I, are very supportive. I think that one should never give up.≫

The biographies erect families that are told, united around the sick parent, without clashes, without conflicts and without reference to relationships and conflicts prior to the illness. They are courageous, supportive, and give strength. They produce an exemplary value and erect a family monument that can enter the circle of other stories to create inter-family stories (Berthelot-Guiet and Charbonneaux 2020).

These family monuments are authoritative because of the very stabilization of their form and the enunciative normalization that they present. Starting from individual statements under the yoke of the enunciation of the digital forum, the messages of the parents of glioblastoma patients combine and formulate themselves in such a way as to enter the field of advice, or even injunction, of authoritarian forms worked "so that neither the unforeseen nor the overflowing find any more place in them" because "the discourses of authority are constituted, in various respects, of stabilized statements" (Krieg-Planque 2015).

The discourses of authority we explore are thus produced largely through the authorization afforded by the digital device itself, as all discourses of authority are inscribed in "discursive materialities" (Candel and Gkouskou-Giannakou 2017, Monte and Oger 2015). Far from being profane of the device, some of the scribblers show that they are strongly aware of its specificities, capable of questioning what the forums and social media groups allow or make difficult in the small factory of authority.

CONCLUSION

It is within the restrictive online discourses frameworks that impose their "order of discourse" that truly "compensatory" information is deployed insofar as it fills what is felt to be a void, especially during the pandemic. This information is a construction cobbled together by families for families in the inter-discourse of the forms of digital dialogism specific to forums, a double escape that underlines the inadequacies of legitimate words and fundamentally questions the question of authority when authority itself seems to lack knowledge.

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