



Oral potentially malignant disorders: Challenges for patient participation due to opacity

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ABSTRACT

Opacity – or the lack of transparency - impacts patients' ability to participate in and contribute to decision-making. This contribution examines how opacity affects patient engagement in the context of oral potentially malignant disorders. The discussion focuses on three key areas: the effects of unclear disease classifications on patient perceptions of their health; the ways in which ambiguous healthcare pathways create barriers for both patients and providers; and the broader impact of opacity on patient autonomy. The conclusion explores strategies to reduce or mitigate these challenges, including fostering epistemic networks for patients and healthcare providers and embracing the value of humility in care work.

1. Introduction

A growing number of scholars are showing the detrimental effects of opacity in healthcare. This contribution investigates the problem of opacity in oral potentially malignant disorders (OPMD), a spectrum of conditions which affect the oral mucosa with heightened malignant risks [1]. Opacity in OPMD is a problem both due to its ambiguous disease categorization and the unclear healthcare pathway for patients and healthcare providers.

Thus far, the problem of opacity in healthcare has been the most extensively developed in discussions of artificial intelligence (AI), where many machine learning algorithms operate as “black boxes,” making it difficult for users to understand how a decision was reached [2]. As AI is increasingly perceived as more reliable than individual expertise, this opacity makes it harder for end-users – including patients and healthcare providers - to question, criticize, or go against its results [3]. This negatively influences their capacity as knowers, as they are unable to decide which information is pertinent or should be challenged.

A parallel discussion in philosophy has shown the negative effects of *institutional opacity* [4]. This concept refers to the phenomenon in which complex institutions resist evaluation and comprehension by their agents or users. Successfully navigating a large institution like a hospital requires expert knowledge. Without a clear understanding of its implicit rules, language, and structures, an institution's agents (healthcare providers, administrators) and users (patients, families) struggle to know whom to approach, where to find information, and how to use the appropriate terminologies to navigate it. The result of feeling lost or disoriented in the system can undermine the person's confidence and

affect their agency, as they do not know how to get the result they wish. While scholars have shown the potentially traumatizing effects on patients when a pre-cancer diagnosis is announced [5], and the need to take into account quality of life factors in OPMD [6], these wider structural factors need to be taken into account in order to understand how they affect patient participation and shared decision-making.

Furthermore, while opacity may affect many patients, it is likely to be especially detrimental to marginalized groups, who already face conflictual relationships with their healthcare providers or barriers to health access. Because OPMD in particular affects lower socio-economic groups (including heavy smokers or drinkers) which are largely disengaged in prevention and monitoring due to socio-economic vulnerabilities, findings ways to better work with these patients is an important public health issue to ensure access to and quality care.

2. Discussion (see Table 1)

2.1. Opacity of the disease category and uncertainty about health status

The first problem of opacity is the disease category of OPMD and its effect on patient conceptions of health. Cancer screening is increasingly identifying conditions or pre-cancers that have uncertain progression to malignancy, raising ethical questions of overdiagnosis [7]. In the case of OPMD, these cancers were originally defined as “pre-cancerous lesions,” but the terminology was changed by the WHO in 2005 to “potentially malignant,” as only about a third of lesions eventually develop into

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Table 1
Opacity and its effects.

Type of opacity	Influence on patient participation	Challenges for healthcare providers
Disease category (pre-cancer/potentially malignant)	Patients unsure about their health status	Communication about risks while avoiding over-medicalization
Opaque healthcare pathways	Late diagnosis; feelings of being “lost in the system”	Referrals to competent healthcare providers
Uncertainty of place for patient autonomy	Patients asked to change health behaviors which may be viewed as paternalistic	Finding a realistic monitoring plan that is acceptable and realistic for patients

cancer [8]. OPMDs have remained controversial for decades in terms of classification, histological diagnosis, etiology, and treatment [9]. In addition, reliable genetic markers with diagnostic and prognostic value are lacking, making it difficult for clinicians to agree on how to classify the level of risk and whether medical intervention is necessary [10]. In OPMDs, the disease category, the level of risk, and the most appropriate treatment remain opaque.

In turn, this opacity affects the patient’s knowledge, appropriation, and conception of their health. From the patient perspective, what does potentially malignant even mean in the context of their lives? While the new classification as “potentially malignant” may be less distressing for patients than “pre-cancer,” this terminology does not necessarily make it more understandable. It brings the same lack of clarity about their health status: the person is currently healthy but potentially will not be in the future; they should reduce risk factors, but it is not always clear which factors might lead to malignancy; they are recommended to regularly monitor their “potentially malignant” lesions, but their level of responsibility remains uncertain.

While this opacity is likely to have a distressing effect on patients, it may also erode the healthcare provider’s confidence in how to communicate the diagnosis, prognosis, and treatment options. While some providers may rely on epistemic networks of fellow colleagues and expert societies for advice, a certain amount of opacity remains due to the uncertainty of disease development. From an ethical perspective, this is a serious problem, as providers risk overmedicalization and do not know the best way to communicate with patients. Indeed, the announcement of a “potentially malignant lesion” may cause patients anxiety, depression, and self-doubt (similar to announcement of a cancer diagnosis), but with the added difficulty of the uncertainty of disease development. In OPMD, high risk lesions may be treated, with uncertain benefits but real repercussions for the patient. As preventive treatment includes surgical incision, and the treatment site is in the mouth or on the tongue, this can lead to functional problems that interfere with quality of life, such as difficulties to speak and eat. At-risk patients are also asked to engage in regular, long-term monitoring and to participate in self-screening to identify suspicious lesions. While these actions may enable early detection, the benefit from the patient perspective may not be so straightforward.

2.2. Opaque healthcare pathways

Opacity also affects the healthcare pathway and the capacity of patients to access early detection. Opacity occurs when patients do not understand how to navigate the complex healthcare landscape and/or when they are unsure who is the right person to address to find the most relevant information. Indeed, patients often complain of being “lost in the system” or of being “overlooked” and “forgotten.” Healthcare is difficult to navigate from the patient perspective given the high level of bureaucracy, technical language, and unclear pathways. For patients with an OPMD, there is often a diagnostic delay due to the lack of clarity about the right person to address. Many patients consult too late because

they do not know who to consult. As the lesion is in the mouth, who should they consult? A dentist? A general practitioner? An oncologist? A dermatologist? Even among the scientific community this question remains controversial, which makes it difficult for providers to guide them and for patients to find relevant information. Furthermore, a dentist in private practice, or a general practitioner, does not necessarily have the expertise to diagnose the lesion, as little attention is given in many countries in training. While some may rely on their networks to find the answers, not all may find the appropriate healthcare pathway.

2.3. Patient autonomy and the importance of health monitoring

While the ethical ideal of patient participation is championed in healthcare today, it also brings forth a number of challenges for the person on the practical level, including a lack of clarity about patient’s right to autonomy. While this is a problem in all chronic and acute illnesses, because of the opacity of the disease category and the healthcare pathway in OPMD, it is unclear in what ways patients can and should exercise their autonomy. For instance, while available evidence points to certain risk factors for oral cancer (notably heavy smoking and drinking), many other causes of OPMD remain unknown due to research lacunes. In addition, as only a small number of OPMDs actually become malignant, it may be unclear from the patient’s perspective why they are being asked to change certain health behaviors and to what extent it may go against their right to autonomy. As many persons with high-risk behaviors are actively encouraged to make changes for “their own health,” it also leads to conflictual encounters with healthcare providers, as recommendations to reduce risk factors are seen as paternalistic. For those with low health literacy and/or who have difficult relationships with healthcare providers due to socio-economic vulnerabilities (which is a common situation in OPMD), this adds difficulties in engaging in shared decision-making. For the healthcare provider, the dilemma between giving advice to the patient on what may be better for their health, the uncertain progression of the disease, and ensuring respect for autonomy remains a difficult balancing act.

3. Conclusion

This contribution explored the negative effects of opacity on both healthcare providers and patients’ agency and the realistic possibility of shared decision-making in spaces of uncertainty. Before concluding, it will be important to understand how to mitigate these problems. First of all, a facilitating factor to deal with this opacity will be to rely on a community of likeminded experts (epistemic networks) to source information and advice, helping navigate this challenging terrain and seek advice from colleagues. The network for OPMD may include oncologists, dentists, general practitioners, and dermatologists to give complementary and diverse views on patient care and to develop referral networks.

Developing epistemic networks may also benefit patients. Indeed, patients often rely on patient associations to make healthcare decisions clearer, giving them greater confidence to participate in shared decision-making. However, not all patients benefit from such networks, in particular for those with rare or ambiguous disease categories, such as OPMD, where there are currently no patient associations. Another issue is that not all patients will feel comfortable or willing to reach out to a patient association, or they may not be able to fully appropriate or understand the information due to low health literacy, meaning that they will continue to be lost in the system. To help patients develop their health literacy, institutions can build multiple resources to respond to patients’ diverse needs, including supporting patient groups for OPMD, but also providing resources – such as information materials – adapted to various levels of health literacy.

Finally, a facilitating factor in the case of uncertain disease categories like OPMD is the practice of epistemic humility. Having an awareness of the limitations of one’s own epistemic capacities and seeking outside resources to overcome shortcomings means being more

open to listening and learning from patients, to hearing their concerns and real capacities and desires to engage in shared decision-making. The practice of humility helps to promote better communication, transparency, and shared decision-making. This is especially relevant for vulnerable groups who have conflictual relationships with their providers. For OPMD, this is important as both the provider and the patient need to work together to make a realistic treatment and monitoring plan in the face of considerable uncertainty of disease development.

Ethics statement

Please note that this is a theoretical piece and not an empirical study; therefore, no ethics approval was necessary.

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Declaration of competing interest

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