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Ethical issues in public health communication: Practical suggestions from a qualitative study on campaigns about organ donation in Switzerland

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ABSTRACT

Objectives: In Switzerland, in spite of a positive attitude towards organ donation, the population seems to overlook the public health messages about it. Based on a qualitative study on campaigns about organ donation, the article aims to give practical suggestions to prevent undesirable effects in public health communication.
Methods: The study provides a linguistic analysis of the messages about organ donation produced by the Swiss Federal Office of Public Health. Such a method enables us to understand *who* communicates *what*, *to whom*, *how* and *what for*, and gives us empirical data to discuss ethical concerns in relation to the effects of public health messages.
Results: The analysis shows that the messages, apart from those relying on the expertise of healthcare professionals, are based on the representation of lay persons. The latter strategy generates the depiction of imagined communities.
Conclusions: Beyond the usual concerns relating to organ donation (e.g., consent, altruism), the analysis of FOPH messages indicates that ethical issues in public health communication are grounded on three relational dimensions (intersubjectivity, cooperation and equity).
Practice implications: A procedure assessing the ethical concerns of public health communication in terms of social identities and relational consequences could identify and prevent problems relating to the undesirable effects of messages.
Availability of data and materials: The datasets used and analysed during the current study are available from the corresponding author upon reasonable request

1. Introduction

In Switzerland, the population's attitude towards posthumous organ donation is generally positive, even if there are slight variations with regard to linguistic and cultural areas [1,2]. Similarly, the news media coverage is well-inclined towards organ donation [3], although its intensity and its angle vary depending on current events [4]. It provides a series of representations associated with organ donation, highlighting the notions of *altruism* and *gift of life* [5], as is the case in other countries [6]. This does not change the fact that there continues to be a shortage of transplantable organs in Switzerland [7–13], where organ donation is grounded on an opt-in system. Organ donation depends on the decision of each individual as stated in the Federal Law on organ, tissue and cell transplantation. If there is no record of the decision, the medical staff can ask close relatives about the deceased's will. Such an organ donation policy emphasises the importance of expressing one's will clearly to others.

Switzerland is not an isolated case since no country using the opt-in system has been able to meet the demand for transplantable organs [14]. In Switzerland, this state of affairs is diversely explained by a difficulty in communicating one's will [2], by a strong divergence between what people believe their relatives know about their willingness to donate their organs and what they actually know [15], as well as by a lack of campaigns that are truly tailored to the different social and cultural groups [16]. In addition to the above-mentioned causes, our study suggests a link between this state of affairs and how the audience can relate to the public messages about

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organ donation. In Switzerland, the public messages about organ donation promote decision-making and the expression of free will. These messages put the individual, faced with the choice of whether or not to donate her or his organs, in a delicate position. In fact, public messages about organ donation imply, for their audience, that the viewers must not only consider their death but also evaluate their altruism towards a suffering, non-visible third party. This twofold implication reflects the main motivation for, and barrier to, organ donation: altruism versus bodily integrity [17]. The tension between altruism and bodily integrity can produce a sort of double bind and result in members of the public ignoring the messages' appeal with the sole aim of avoiding any ethical dilemma, in the same way that the relatives of potential donors refuse the act of donation because they are caught in the double constraint of helping people and protecting the body of the deceased loved one [18].

Our research focused on the messages about organ donation produced by the Federal Office of Public Health (FOPH) between 2007 (the year of the first national campaign in Switzerland) and 2012. At that time, the FOPH had the legal and political duty to put the choice of donating on an equal footing with the choice of not doing so. It was a critical situation inasmuch as public health campaigns, in addition to informing the population, are usually designed to promote specific types of behaviour [19]: not to smoke, get vaccinated or take a donor card, for instance. The fact that the FOPH did not have the right to adopt a position either against or in favour of organ donation impacted on the campaigns between 2007 and 2012, and shone a new light on the ethical issues relating to public health communication. It weighted on the relationship that the FOPH built with its audience and, consequently, on the relationship the members of the audience were able to build with a suffering third party that they could potentially help by deciding to donate their organs in the event of death. It highlighted the potential ethical dilemma relating to the tension between an altruistic stance and the preservation of bodily integrity that the call for organ donation can produce. In March 2013, faced with a persistent organ shortage, the Swiss government launched a new action plan "More organs for transplants". This affected the strategies of the FOPH, which was no longer required to remain neutral, as illustrated by the slogan of the 2015 campaign ("organ donation saves lives"). Nevertheless, the FOPH continued to promote decision-making and the expression of free will without solving the aforementioned dilemma.

Hence, by focusing specifically on that period of time (2007–2012), we have been able to identify clearly this far-reaching risk of a double bind and thus suggest ways of preventing the potential problems and ethical concerns associated with public health communication that could burden further campaigns.

2. Methods

This study has been carried out within an interdisciplinary project aimed at unpacking the different psychosocial challenges of transplant medicine [20]. Between 2011 and 2012, we collected all of the messages the FOPH published on organ donation and transplantation from 2007. We did not need to do an exhaustive review of the various press media in Switzerland because all of the messages were publicly available on the FOPH website at the time. We did not include those published by Swisstransplant, the Swiss foundation in charge of coordinating the allocation of organs, because its specific mission led to a different stance from the FOPH on the issue. The FOPH messages consisted of written texts (with or without images) and audio-video recordings. We gathered these messages in a structured data-set that allowed for a systematic coding through a process of intercoder agreement [21].

The data-set was structured following four parameters: languages (German, French and Italian); types of media (donor card, leaflets, advertising posters, TV adverts, websites); contents of messages (FOPH messages about organ donation and transplantation medicine, FOPH messages about its communication activities on organ donation); and texts' spread out in the public sphere (both long-term and short-term). Relating to this latter category, it is worth specifying that the FOPH texts with a long-term presence in the public sphere include: messages disseminated via the websites "bag.admin.ch/transplantation" and "transplantinfo.ch", the donor card, a general information brochure and educational tools. The FOPH texts with a short-term spread in the public sphere include: messages disseminated during annual or biannual campaigns via press releases, posters and TV adverts, internet banners and non-permanent sections of the website "transplantinfo.ch". There were no messages designed specifically for social media.

The data were coded and analysed using a qualitative methodology that applies linguistics to health communication [22]. The choice of such a methodology was motivated by the fact that the relationship which the public messages build with the audience is always mediated by language and various semiotic processes. Such a methodology enables us to describe for each message *who* communicates *what*, *to whom*, *how* and *what for.* By doing so, we combined two linguistic sub-disciplines [23,24]: pragmatics, which deals with the relationship between language, meaning-making and action, and sociolinguistics, which focuses on the relationship between language, social realities and the life-world. Our study focused on meaning as it is encoded in messages by linguistic signs rather than their actual uptake by members of the audience. This choice was motivated by the fact that these messages can be interpreted by a plurality of individuals in a diversity of settings, without it being possible to account for the profusion of possible interpretations.

The whole research process has benefited from the insights and feedback of an advisory committee including linguists, psychologists, ethicists and stakeholders in the field of organ donation and transplantation (medical and nursing staff, patients, policy-makers).

3. Results

The analysis of speech acts (what is being communicated, how and what for?) and communicative roles (who communicates?) shows a tension between political decisions (*informing about organ donation without promoting it*) and practical achievements (*encouraging people to take a decision and talk to their relatives*). This tension is solved by a particular type of articulation positioned between information and encouragement [25]: the long-term texts favour information while the short-term ones focus on encouragement. The informative strategy of long-term texts is based on a rhetoric of objectivity. This rhetoric is grounded on the expertise of health professionals and researchers. It is characterized by the erasure of subjective marks in messages (e.g., first- and second-person pronouns) and the use of impersonal writing (e.g., passive and impersonal structures). In the short-term texts, the encouragement strategy makes use of a rhetoric of subjectivity. It presents individuals who express themselves. It exploits a particular form of "non-expertise", that of a lay person who nevertheless knows how to proceed to do the right thing. The overall communication strategies remain the same in German, French and Italian. For instance, whatever the language is, the 2008–2009 campaign encourages people to follow a decision-making process in three stages, first focused on the individual's choice (*getting information, taking a stance*) and then oriented toward its communication (*expressing it to others*). Nevertheless, language diversity impacts on the messages' formulations [25]. In the 2008–2009 campaign, depending on the language, different parts of the texts are highlighted, using bold letters and larger font size:

- German version: ***Ich*** *entscheide selbst* (**I** decide for myself), ***Ich*** *weiss was ich will* (**I** know what I want), *Weiss jemand, was* ***du*** *willst?* (Does anyone know what **you** want?);
- French version: *C'est* ***moi*** *qui décide* (*It's* ***me*** *that decides*), ***Je*** *sais ce que je veux* (**I** know what I want), *Qui d'autre sait ce que tu* ***veux*** *?* (Who else knows what you **want**?);
- Italian version: *Decido* ***io*** (**I** decide), ***So*** *cosa voglio* (**I know** what I want), *Sanno* ***cosa*** *vuoi* (Do they know **what** you want?).

In German, the emphasis on "ich" and "du" underlines the transition from inner reflection to dialogue, which was one of the main goals of the campaign. In the French and Italian versions, the typography focuses on the individual's stance ("moi", "je", "veux"; "io", "so", "cosa") without highlighting the importance of expressing it to other people. This indicates a loss of consistency between typography and the overall communication strategy. Such an analysis shines a light on the challenges of multilingualism in public health communication: even if the content which is being communicated is similar, the way of communicating it necessarily varies [26].

The analysis of communicative roles (who communicates?) and of the ways of speaking about organ donation (how is it communicated?) in the short-term texts transmitted between 2008 and 2012 shows that the FOPH encourages the discussion and the decision-making about organ donation while maintaining a complete neutrality with regard to the topic. To do so, the FOPH uses a communication strategy based on the presentation of individuals who represent stereotypical socio-demographic categories (in the 2010 campaign, for instance: men/women and young/old). The representation of "ordinary" members of the Swiss population goes hand in hand with a process of delegating to them the right to speak about organ donation. This delegation leads to a standardisation of the ways in which organ donation is thematised, since talking about this issue is reduced to the basic level of being against or in favour of it and an expression of one's own opinion, just as in the 2011–2012 campaign where 45 people are invited to talk about organ donation with similar formulations (*I am in favour of/against organ donation*), whatever the language is:

- German version: *Ich bin für/gegen Organspende*;
- French version: *Je suis pour/contre le don d'organes*;
- Italian version: *Sono per/contro la donazione degli organi*.

In fact, such a representation strategy and delegation of speech responds to a double constraint of decontextualising and anchoring public messages [27]. On the one hand, the messages must make sense to all members of the target audience in any given situation. On the other hand, messages must be relevant and relate to the singular reality of each individual who receives them. Such a strategy creates imagined communities for which organ donation is made relevant. Equally, it leads to the formation of exclusion zones for those who are not part of these communities.

A content analysis (what is being communicated exactly?) shows that the messages disseminated by the FOPH relay the ethical issues usually associated with organ donation and transplantation medicine [28,29]. The topics discussed are as follows:

- *organ trafficking and trade* ("it is prohibited to trade in organs", campaign 2007);
- *equity of treatment* ("the doctor who records the death cannot participate in the removal or transplantation of organs", campaign 2007);
- *consent* ("the will of the deceased person prevails over that of relatives", campaign 2007);
- *autonomy of decision* ("I make my decision", campaign 2009);
- *bodily integrity* ("I want my body to be intact when I die", campaign 2011–2012);
- *altruism* ("I am in favour of organ donation. I received life as a gift and I would like to give this gift to someone", campaign 2011–2012);
- *solidarity* ("since my birth, I have only one kidney, if something happens to me, I too will depend on a donation", campaign 2011–2012);
- *utility* ("I think it's beautiful to know that you can be useful after your death", campaign 2011–2012).

In summary, apart from the ethical issues related to equity in the allocation of organs and the call for social solidarity, messages echo values attached to the dignity, autonomy and well-being of the individual. In addition, the FOPH messages set out a standard of good conduct relating to the decision to donate or not to donate organs. They relate to two scenarios which share a common orientation towards a form of standardisation. In the first case (e.g., campaign 2008–2009), the FOPH shows all the components of the exemplary three-stages conduct of an individual who knows what to do and when. In the second case (e.g., campaign 2011–2012), the FOPH shows a heterogeneous sample of concerns, which adds a form of experiential depth to the three-stages decision-making procedure that is promoted. All these strategies are based on a cognitive-behavioural vision where information is the main basis for human behaviour (getting more information in order to act better) [20], which runs the risk of forgetting that decisions are made within the context of a given social situation [30].

4. Discussion and conclusion

4.1. Discussion

Our results confirm that public health communication may raise ethical dilemmas relating to personal choices [31,32] and well-being [33–35]. For instance, FOPH messages encourage people to make a decision that leads them both to consider their death and evaluate their altruism towards a suffering other. By doing so, FOPH messages both invoke and restrict the autonomy of the individuals. Ethical dilemmas in public communication may also pertain to the risks of stigmatisation and exclusion of some parts of the population [36] and the need for a consideration of cultural and social diversity [37]. In our data, this is well illustrated by the instances of standardisation (standardisation of communication, standardisation of decision-making procedures).

The complexity of ethical dilemmas in public health communication may be best understood through three relational dimensions that are inherent to communication: the imperatives of *intersubjectivity*, *cooperation* and *equity*.

4.1.1. The imperative of intersubjectivity

Communication needs common ground [38], that is contents the communicators think they share with the people they (want to) communicate with. This results in an imperative of intersubjectivity for those who communicate. Their interlocutors do not necessarily wish to engage in such an issue or do not have the psycho-social capital and symbolic resources to deal with it. These issues are well illustrated in our data. Because of the preventive aims of public health [39–41], public health messages generally initiate the relationship with their audience rather than respond to a prior request for assistance or care. By initiating the relationship with the audience, FOFH's messages bring along not only a topic (*organ donation*) but also an order of discourse [42], that is a system of beliefs and values that makes the topic relevant (the *transplant medicine*'s and *social solidarity*'s frames of reference). For instance, the messages about posthumous organ donation project the future death of the individuals to whom they are addressed. Thus, through these messages, the issue of death breaks into public arenas, and this occurs

without any prior relational work that could help to manage its sudden entrance. Such an irruption seems justified by a balance between the costs and consequences of the communication at different moments: for instance, the discomfort produced by a public health message could subsequently be offset by the benefits that the same initiative then has for those individuals in need of organ donation.

However, the projection of death involves communicative risks, including the effect of reactance [43], that is the risk of the audience's members wholly ignoring the issue of organ donation in order to preserve their bodily integrity from any danger. This is all the more delicate in the context of mass media where adjustments to audience reactions are more difficult to make. As a consequence, public health communicators must carefully evaluate the relationship in which they engage an audience that has not necessarily solicited their messages. This change of scale plays an essential role from the point of view of the means (mass media and message prefabrication) and ways (decontextualising or stereotyping) adopted to reach the audience.

4.1.2. The imperative of cooperation

Communication is bound by an imperative of *cooperation*. The cooperation of the one who communicates is a prerequisite for the proper interpretation of messages [44–46]. Consequently, the audience assumes that the one who communicates is sincere. In other words, it is a matter of not presenting what is believed to be false as true and not hiding the actual communicative intent that motivates the dissemination of messages. This is what determines whether a message is considered to have value or not. The FOPH messages exemplify a case where two antagonistic positions (*being for or against organ donation*) are considered acceptable since the law establishes a free choice regarding organ donation. To cope with such a constraint, the FOPH chose to present a set of voices that are representative of the various possible positions. In this case sincerity corresponds with a position of neutrality.

The imperative of *cooperation* also implies considering the false impressions that can be conveyed by otherwise seemingly truthful messages, such as careful manipulation of some dimensions to the detriment of others or the use of misleading imagery [47]. It is, therefore, up to the producers of the messages to be able to assess the interpretative capacities of their audience in order to avoid doing any offence or harm. The communication's quality is thus related to its presumed effects, joining a consequentialist principle of non-malfeasance [48]. These consequences, however, need to be assessed in detail: for example, while experiencing the sudden intrusion of death into one's daily life (due to a message about organ donation) may cause some distress to the individual receiving the message, this harm may be considered benign compared with the ultimate consequence of a communication campaign aimed at saving lives through organ donation and transplantation. Thus, while the costs may seem important from the extremely situated point of view of the individual taken in the here-and now of her or his existence, the potential benefits may justify the communicative actions and strategies undertaken.

4.1.3. The imperative of equity

Communication calls for fair conduct between the various parties, who in public health communication are necessarily multiple because of the diversity of the audience's members to whom the messages are addressed. In such a communicative context, *equity* implies, at first glance, that information is accessible to everyone. The fair distribution of information is subject to material and symbolic constraints. In addition to material access issues, communicative barriers must be understood as those that could constrain or prevent the proper interpretation of messages. It should be added that the population to whom public health communication is addressed is generally not a homogeneous group but, on the contrary, often made up of a multitude of subgroups whose values, knowledge, practices and health status can vary considerably. Consequently, public health communication calls for a distributive justice, following a principle of proportion, in which the distribution of opportunities is considered in relation to existing inequalities. Distributive justice promotes social solidarity, particularly with regard to vulnerable groups. With an underlying consequentialist logic that is directed at the well-being of the greatest number of people, public health communication runs the risk of increasing inequalities in access to health and of discriminating or marginalising parts of the population [48]. Such a risk can, nevertheless, be reduced by initiatives targeting groups whose characteristics are particularly relevant to the health issue at stake.

In other words, by anticipating the forms of exclusion brought about by a given communicative strategy, the producers of public health messages could ensure a form of social justice. For instance, public communication about organ donation in Switzerland shows a conflict between the representativeness of the actors employed to portray certain individuals in the messages and the exclusion of some minorities. In this respect, the use of fictional characters in the FOPH messages can be conceived as a benevolent manipulation, gambling on the competence of an audience capable of understanding the communicative intention behind the message. Nevertheless, it remains the case that, by showing what a "typical" Swiss is or should be, the strategy chosen by the FOPH has a secondary effect: the exclusion of parts of the population. In the same vein, the public messages of the FOPH present the same communication strategies from one language to another, even though it has been demonstrated [1,16] that the way in which it is appropriate to talk about organ donation varies according to linguistic areas.

4.2. Conclusion

Our study indicates that ethical issues in public health communication are grounded on three relational dimensions and their potential implications for the audience. As no messages were especially designed for social media, further research should be carried out on the ethical issues relating to the use of social media in public health communication: in such settings, the audience is able to interact publicly and directly with public health messages. In spite of this limitation, ethical issues could be identified and thus, hopefully, prevented through the use of a systematic procedure of evaluation prior to the airing of public health messages.

4.3. Practice implications

Our results and their discussion speak in favour of public health communication strategies that are tailored to the audience and to the topic at hand. For instance, the ethical dilemmas raised by the FOPH messages might be better managed through types of communication that allow feedback and co-construction if needed, such as interpersonal communication, group communication or, to a certain extent, social media.

A systematic procedure of evaluation assessing the ethical issues of public health messages should take into account the relational dimensions of communication (1–3) and its potential implications for the audience (4–6):

(1) Which members of the audience are favoured by the channels (visual, auditory, etc.), media (print, radio, social media, etc.), modes (oral, written, etc.) and repertoires (languages, registers, etc.) that are used? And, on the other hand, who do they exclude?
(2) What is the identity of the communicator before the act of communication? Is this identity the same while the

communicator is communicating? Does the communicator take the act of communication on or is it delegated to another figure (an expert, a lay person, etc.)?

(3) To whom is the communication addressed? And which identities are assigned to the individuals to whom the communication is addressed? Are these identities desirable for them? And, if not, what are the reasons why it is still an appropriate communication strategy?

(4) What is the communicative intention? What does the communication strategy want to achieve (to make people do things or believe things)?

(5) In the message, is the communicative intention explicit to the audience or is it covert? And if the communication is covert (for example, making people believe things to make them do things), is it perceptible on the part of the audience?

(6) What is the main effect intended by the communication strategy? What are the alleged side effects? And are they acceptable?

Such a procedure, without being the sole means of assessing the appropriateness of public health messages, is designed to enable their producers to adapt their strategies in the face of ever-uncertain contexts with an ability to integrate the plurality of points of view as well as the diversity of situations [49]. By being quite simple and applicable at little cost, this procedure aims to advance towards truly tailored and cost-effective public health campaigns.

Ethics approval and consent to participate

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Gilles Merminod is the first author of the contribution, **Lazare Benaroyo** is the second author. The current study stems from **Gilles Merminod's** Ph.D. thesis in life sciences, supervised by **Lazare Benaroyo**.

Declaration of Competing Interest

The authors declare that they have no competing interests.

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Consent for publication

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