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Scientific Citizenship and Young People. Storytelling Perspectives for Public Health



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ABSTRACT

Scientific Citizenship and Young People. Storytelling Perspectives for Public Health

New life sciences and biotechnologies have challenged our classical understanding of being human, on an individual and private level as well as on a public level. Educational experts and policymakers have engaged in the development of new ways to make research and innovation processes accessible to every citizen, elaborating strategies aimed at allowing an open, inclusive, and informed discussion. The task of biomedical communication is complex not only because of the contents that are sometimes difficult to simplify, but also because of the communicative environment. Certainties and unequivocal answers are often expected from science, without considering that uncertainty is an integral part of the scientific method. In this context, experts tend to overestimate the power of data which, for the majority of the public, are meaningless fragments. The storytelling can be a suitable tool to get out of this communicative impasse especially for young people.

Keywords: Biomedical communication - Young people - Public health
- Storytelling

Scientific citizenship and young people

New life sciences and biotechnologies have challenged our classical understanding of being human, on an individual and private level as well as on public one. Therefore, educational experts and policymakers have engaged in the development of new ways to make research and innovation processes accessible to every citizen, elaborating strategies aimed at allowing an open, inclusive, and informed discussion on the research and technology decisions that will impact citizens' lives, both on the individual and social level. Since the Royal Society "Public Understanding of Science (PUS)" report was published in 1985, science-society engagement actions have moved from a so-called "deficit model" to more inclusive approaches. At the heart of such strategies lay the idea that the increase of scientific knowledge in society benefits not only scientific understanding but also the capacity of more rational and critical decision-making in those aspects of daily life.

Science education still remains the most accessible and accountable strategy of knowledge dissemination in the contemporary scenario. As it has been recently pointed out, science education in our society should help citizens to access and interpret the science they need to face specific practical problems, as well as to judge the credibility of scientific claims based on both evidence and institutional cues, and to cultivate involvement in science¹. The dissemination of science, in particular biomedical science, is developing today in a series of media spaces that are extremely heterogeneous in terms of content and expressive methods. The quantity and heterogeneity of these communicative practices are part of a more general framework of transformation of social representation of health and illness and of attitudes and behaviors that are connected to them. This access to information is what guarantees citizens the opportunity to participate actively and consciously in the management of their own health. This need has also been reaffirmed in the legislative context through, for example, the introduction principles such as that of "informed consent". In these terms, therefore, the subject can choose between a growing number of therapeutic options and styles of health care and ultimately, access and manage the various images and concepts of health that become available from time to time.

In the formal and informal science education, the ICTs (Information and Communication Technologies) strategies could have an important role². In particular, new ICTs are globally deployed and have significant impacts on the way people access health information. New ICTs are an effective mechanism for detecting, responding to, preventing, and controlling health concerns. The context in which people are exposed to health information has changed with the diffusion of mobile media. Interactive health communication influences the health care system with its information dissemination, health promotion, and support for health services. Robinson et al.³ defines interactive health communication as the interaction of an individual consumer (patient, caregiver or professional) with or through an electronic device (or communication technology)

in order to access or transmit health information, or to receive guidance and support regarding a health-related issue. Increased consumer participation in interactive health communication influences the health care system with its information dissemination, health promotion, social support and health services functions. Perhaps the most common and influential function of interactive health communication today is that consumers, especially who have difficulty communicating face-to-face, may seek health information and may be able to engage in interactive health communication. The consumers access online health information in three primary ways: searching directly for health information, participating in support groups and consulting with health professionals⁴.

In public health, ICT's can influence the perception of disease severity, views about the potential risk of contracting a disease, or feelings about the need for prevention or treatment. ICT's can also break the cycle of misinformation and lack of information regarding health conditions that are underdiagnosed, undertreated, or underreported. Carey (1998) pointed out that new ICTs are creating a new media ecology that alters structural relations among old media. Health issues are universal and concern everybody in the world. In our global society where diseases know no borders, countries are increasingly recognizing the importance of improving health conditions. New ICTs are globally deployed, and have significant impacts on the way people access health information. At no time in history have media been more prolific and widely available on a daily basis to citizens. Users may increasingly become the producers and vectors of informative content rather than mere recipients, boosting peer communication regarding health and the risks of unhealthy lifestyles.

Nevertheless, additional efforts are needed to stimulate media' use at a micro (target group, intermediaries) and a macro level (socio-political and institutional). It has been recommended that this could be encouraged with peer-to-peer initiatives, as members of the target group tend to closely identify with their peers. Most public health campaigns and public health interventions seek in some way to change health behaviors by improving health-related knowledge, attitudes, and/or structural barriers. The explosive growth of the Internet has caused an increase in Internet-delivered public health campaigns that fit in perfectly with the ubiquity of the Internet in people's daily lives. Because of its availability, anonymity, and low cost of access, Internet is an increasingly common way for adolescents to find information on sensitive issues. Moreover, online peer support could serve as a gateway to online professional support.

Technology-mediated communication is influenced by many factors that affect other types of interpersonal communication, including health literacy and e-health literacy levels, age, gender, cultural, ethnic and individual factors. Alongside information, there are further levers that, in a transversal manner with respect to the determinants of health, can contribute to the real adoption of a healthy lifestyle. This is what is defined as a "behavior management continuum", which consists of three tools: commu-

nication, social marketing and regulatory interventions. The use of these three tools, in an alternative or integrated way, can be distinguished according to the target attitude (they are more or less culturally ready for change), to the perceived advantage of a specific action, to the attractive force of competing behavior (alternative to the unhealthy behavior). Of course, socio-economic and cultural inequalities in terms of health, health perception and the concrete possibility of changing incorrect behavior can be considerable. Just as inequalities in terms of health literacy and even more in e-health literacy can be relevant. However, it is impossible not to consider, in our digital society, the use of web channels to strengthen the communicative impact and relationship of action strategies in this sector, especially when directed at a young target.

Public health promotion

In the contemporary cultural and social scenario, self-reflexivity should be appropriately stimulated and therefore, in terms of health, aimed at placing in individuals' own hands the ability to make conscious health' choices. In order to know and manage their own body and its functions autonomously, without resorting to passive and often forced medicalization, nor to an alarmist reading of the risks. The quality of health is strongly influenced by lifestyle habits. Lifestyle habits allow people to exercise some degree of control over their health. By learning to manage their lifestyles, people can live longer and healthier and delay the aging process. Self-management of one's body and health could be called a "good" medicine without "side effects". Most habits of life that endanger health are defined during childhood or adolescence. For instance, teenagers who have don't pick up the habit of smoking during their adolescence, will hardly get into the habit as adults.

We also know that it is easier to prevent harmful habits than to try to change them later, once they are deeply ingrained and have now become an integral part of the lifestyle. These are the main reasons that should lead youth prevention to be a priority in social policy. The approach to health promotion must necessarily be guided by the theory of self-determination⁵, which encourages using strategies that are based on intrinsic motivations to act ("I want to change"), as opposed to extrinsic motivations for change ("I have to change"). And it is important to emphasize the role that comparison and support between peers can have on self-determination, especially when it comes to young people. Peer initiatives inherently recognize young people's skills and abilities and their constructive role in problem solving. They can also increase young self-esteem and their sense of effectiveness and control in their lives. All these factors also play a role in determining their health-related behaviors and their ability to access appropriate health services. Thus, initiatives aimed at raising awareness among peers are undoubtedly invested with an important role also within the strategy of promoting health and public health. In fact, young people have numerous informal exchanges where they listen to each other and share anxieties and concerns. However,

young people often lack information on the services that are made available to them or do not know how to access them. Therefore, supporting peer information offers the possibility of disseminating these skills, which are often vital.

Individual attention to health and prevention goes hand in hand with the perception of risk. Risk perception in young people is often linked to the “optimistic bias”, an error of human thought that deludes people into evaluating their own risk of being victims of an adverse event as lower, compared to that of those around them, for the exact same event. The term was coined by Weinstein in 1980. The phenomenon has also been called, “unrealistic optimism”, “comparative optimism” and a number of other labels, including the “illusion of unique invulnerability”⁶. The practical importance of optimistic bias derives from the assumption that it makes people choose risky behaviors and causes them to avoid, in the area of health, protective and preventive activities. In this vein, can be considered a major obstacle to attempts at improving public health or reduce the risk or mitigate the consequences of accidents⁷.

For instance, a study conducted on the perception of the topic of infertility, which had a group of university students as samples, confirmed the bias of youthful optimism⁸. With reference to the theme of the riskiest lifestyles associated with infertility, it is interesting to note that most of the interviewees claimed the benefit to stay informed about reproductive health in order to prevent this disorder. With regard to the perception of the risk of infertility, a finding already present in the literature is confirmed, according to which the one’s own risk of infertility problems is considered, by respondents, lower than that of peers of the same sex. However, the most interesting finding is that the proportion of those who do not raise the problem of reproductive health at all, both for themselves and their peers, is still quite high. The lack of information on infertility from experts is a constant and sources of information can therefore have different and sometimes opposite impacts on the perception of risk. This research has shown that young people are becoming more sensitive to the issue. It is also worth noting that when they seek information it is mainly through scientific sources (at least in this university sample), although it is necessary to continue to increase information and awareness on the subject. It is above all necessary to involve the target group of young men more closely, and it is necessary to strengthen the scientific awareness regarding the issue of infertility to avoid prejudice and misconceptions and to help all young people, regardless of their education level, to take the most responsible and correct decisions in this regard.

The infertility is an important public health issue. Nevertheless, the Ministry of Health recorded a failure with the 2016 “Fertility Day” campaign⁹. It was a paradigmatic case of limited attention in the management of communication strategies and social environments. Once on the web, the campaign materials became a topic on the media and politics agenda. Described as sexist and then racist, the campaign was heavily criticized because built around the idea that women should be pressed to have children



Fig. 1

as soon as possible. Some claims stated: “Beauty has no age. Fertility yes”, “Hurry up, don’t wait for the stork ” (Fig 1). A part of public opinion stressed that rather than inviting women to reproduce as soon as possible, the message should have taken into account the need to increase the number of public nurseries, to encourage female employment, to remove all those obstacles that prevent women from self-determination, and therefore, also from deciding to have children. Furthermore a brochure was published entitled “Correct lifestyles for the prevention of sterility and infertility”. Two groups of people on the cover were associated with a lifestyle. The group of “good habits to promote”, was represented only with white people, smiling and with tidy hair. In the other group there were black boys who smoked, with long hair, accompanied by the words “the bad comrades” to be abandoned. This brochure was also criticized and accused of racism. The contents became an ironic object by users and a source of controversy by associations and movements¹⁰ (Fig. 2).



Fig. 2

Promotion, prevention and nudge

The World Health Organization (WHO) has stressed the crucial role played by social media in healthcare institutions to promote public health initiatives and to disseminate reliable health information. The most widespread form of health awareness passes through prevention and promotion campaigns. Promoting health means combining health education and public policies in a synergistic and productive way. The methods of intervention to promote healthcare activities and prevent risky behavior can be authoritarian or negotiated and have an individual or collective focus. Changes in health behaviors are a complex process that are difficult to predict and interpret. Certainly, numerous variables must be considered: such variables are distributed on an interdisciplinary level ranging from psychology to marketing from sociology to communication. Without neglecting individual variability, behavior changes can be generally affected by the interaction with cognition and context. In other words, behavior, i.e. what a person does, including the search for information on one's health, interacts with cognition, i.e. what a person thinks: how he or she defines and considers reality, his or her beliefs and perceptions, values and memories. In these terms, cognition is influenced by the "culture of health", by the experiences that can be different throughout different stages of life. Furthermore, the context in which people live and act should not be overlooked, i.e. the cultural, social, physical, emotional and psychological environment that can inevitably facilitate or hinder a change.

On the other hand, a single communication campaign, if the reference context of the message is not considered, can hardly lead to a concrete result. Moreover, the same unsatisfactory result is obtained if due attention is not paid to reducing what may be the material or cognitive barriers, with respect to the action that is sensitized through the campaign.

First of all it is necessary to distinguish prevention from promotion. In the metaphorical representation of the term "prevention", the individual advances within a "protective shield", and the underlying emotional-motivational component is fear. In the metaphorical representation of the term "promotion", the individual is oriented towards the challenges of life, and the underlying emotional-motivational component is the hope. If *pre-venio* indicates the action of arriving before a feared and ineluctable event, such as a crisis or an illness, *pro-moveo* indicates the action of going towards a coveted situation.

Prevention includes a wide range of interventions with the aim of preserving health and avoiding the progression of diseases. The concept of health promotion, on the other hand, has spread since the 1970s starting with the actions of the WHO and then from 1986 onwards by the International Conferences on Health Promotion. Over the years, the concept of health education evolves towards the concept of health promotion that addresses individuals and groups in the settings in which they live and work. Health promotion has two levels: -improvement of lifestyles; -improvement of living

conditions. Health promotion also involves a shift in the language of public health professionals: from an educational tone to a community development line. The community' prevention includes the set of interventions that define primary prevention, such as: health education campaigns, environmental interventions, and legislative provisions. The goal is to achieve the empowerment of a community, so that individuals are both subjects and objects of the interventions, and develop self-efficacy. The aims are: developing individual capacities (providing information, ensuring health education, allowing individuals to exercise greater control over their own health); create healthy environments (by ensuring living and working conditions that are safe and satisfactory); promote community' action (providing for the effective and concrete participation of the community in defining priorities, making decisions, elaborating strategies to achieve a better level of health). Therefore, less emphasis is being pointed on individual responsibility and on the "victim blaming".

According to the appraisal theory¹¹ the tonality of our emotional reactions depends on our process of cognitive evaluation ("appraisal") of the events around. This explains why the same event can generate different emotional reactions in different individuals, or at different times. Especially the negative emotion of fear can be functional in the prevention of health-related risks, prompting behavioral changes. This so-called "danger control" process is very useful for a prevention awareness campaign, because the fear gradient must be counterbalanced with the "self-efficacy factor", the degree to which the individual feels self-confident to protect himself from risk. Even the use of positive emotions, such as irony, can be effective in promoting healthier behaviors especially for more distracted or less available targets, such as young people¹². However, as argued by the Health belief model proposed by Rosenstock¹³ and modified by Becker¹⁴, beliefs about health can also play a significant role in our behaviors, in risk perception and management. While Richard Thaler (University of Chicago) and Cass Sunstein (Harvard University), have coined the concept of nudge, or "mild push". They argue that in prevention the optimal intermediate path between forcing a change and consciously convincing people to change their behavior is the configuration of the architecture of choices, within which the behavior fits. In their opinion, the nudge could modify the context (the architecture) of the choice in order to make it easier for individuals to decide the most correct and healthy action to take¹⁵. On the other hand, according to Bandura's Social Learning Theory¹⁶, from a psycho-social point of view, we tend to imitate the behavior of those we admire and whom we consider a source of inspiration. Along this line, we discovered the power of strategies that make use of the influential, echo chambers¹⁷ and confirmation bias, to promote behavior changes. This happens mostly through social media where certain content can go viral thus achieving enormous persuasiveness. Lastly, the concept of citizen-patient empowerment has recently been extended to other contexts of prevention and health promotion. In particular, the People Health Engagement Model (PHE-Model)¹⁸

can be considered a tool for directing communication and targeted education to encourage engagement and conscious motivation for behavior change.

Storytelling perspectives for public health promotion

Nowadays the scientific panorama has reached a considerable level of complexity and it becomes difficult to acquire the knowledge necessary to handle disciplines in continuous and rapid evolution. In such a context, the relationship between science and society can become a minefield because of the polarization that dominates the public discourse, above all regarding controversial topics perceived as impacts on one's life and one's health. For this reasons, the task of the biomedical communication is complex not only because of the contents that are sometimes difficult to simplify, but because of the communicative environment made hostile by polarization amplified by social media. Certainties and unequivocal answers are often expected from science, without considering that uncertainty is an integral part of the scientific method. In this context, the experts tend to overestimate the power of data which, for the majority of the public, are fragments meaningless¹⁹.

Storytelling can be a suitable tool to get out of this communicative impasse. To change ways of thinking or behavior, we need a new experience, and the story provides a vicarious one. Furthermore, it is not possible to change someone's opinion without a prolonged communicative effort: false beliefs are difficult to eradicate and a story embarks on a journey made up of steps, without rush^{20,21}. The narrative approach to science communication is useful because it provides the data with a context. In this way, cold and impersonal facts are humanized and opened to the emotions. This is true for all scientific sectors, but in particular for those that have a direct relevance on people's life, such as biomedical science. Storytelling can help make topics more accessible, also by promoting the figure of the researcher, bringing such professional closer to the public and encouraging identification. If it is true that science is made up of stories, it is equally true that the health sector, and all that converges towards it, is the one richest in stories because the representation of people is its main fulcrum^{22,23}. Lisa Saffran, professor of Storytelling in Public Health and Policy at the University of Missouri, is of the opinion that those who work in the public health field have a moral responsibility to become more competent in telling and creating narratives accessible to all. The narratives could be able to dialogue with the people, to provide them with tools to achieve empowerment in the field of health, and could support and improve the decisions regarding the health policies of a country²⁴.

Persuading and educating represent two different roles in science communication aimed to achieve different objectives: the general consensus linked to a specific topic, or providing the target with tools useful for independent and informed choices. Often persuasion has a negative meaning that brings it closer to the concept of manipulation, however persuasion can also be desirable when the benefits of the community exceed

those of the individual^{25,26}. The storytelling in the biomedical field can be effective in particular to: transmitting knowledge; stimulate reflection on controversial issues such as climate change, OGM, vaccine safety; influence attitudes and behaviors, to encourage the acquisition of a healthy lifestyle. The storytelling can support the scientific method comprehension, to rebuild the foundations of the trust relationship between experts and citizenship, because often understanding how science works is more important than the results achieved²⁷. For this reason, it is important to shake off the negative prejudices that saw it as an “agnostic tool to the truth” consequently incompatible with science, and to understand that narration is not a dimension opposed to logical-scientific reasoning, but could be use at the service of science²⁸.

Personal storytelling also has a great potential in the field of health, through thematic channels and through personal channels, also participating in the patient associations initiatives. It is an informal type of communication, closer to the public because of sharing an expertise as result of personal experience. Furthermore, this individual narrative practice can also fulfill a further function: self-expression helps the personal path of coexistence with the pathology and, at the same time, allows the support from one’s own community of reference²⁹. A story that is born as a personal therapy does not preclude that the same story could be integrated into a storytelling project. Similarly, if the caring narratives are shared with the care team, they can become part of a narrative approach to the therapeutic path called “narrative medicine”³⁰. The storytelling is persuasive and for its ability to transport the listener into a narrative universe and engage his cognitive resources, reduces the ability to critically evaluate. However we must consider that this power raises significant ethical questions, especially in scientific biomedical communication, linked to people’s health and lifestyles. In this context, in order to the narration accuracy there are two levels to consider: realism and representativeness³¹.

In conclusion, storytelling is a powerful communication tool that seems to be essential for living in today’s communication environments, saturated by content. It is important to embrace a way of communicating health that is increasingly aimed at personalization. However, this complex tool, when applied to large companies, requires important design work involving many professionals. Training is essential to be able to build a storytelling operation and manage it effectively, because of the channels on which we want to share the narrative require with different languages and skills. It is also important to evaluate the impact that the storytelling initiative will have on the target group, especially talking about topics such as health, and to identify areas of potential negative effects of a wrong narrative.

In the contemporary context of digital transformation and hard accountability in the scientific biomedical area, storytelling could represent the present and the future of public health communication, especially for young people.

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