

Research for Development

Antonella Valeria Penati *Editor*

# In-Home Medication

Integrating Multidisciplinary  
Perspectives in Design-Driven Pharma  
Practices



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# Research for Development

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Antonella Valeria Penati  
Editor

# In-Home Medication

Integrating Multidisciplinary Perspectives  
in Design-Driven Pharma Practices



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ISSN 2198-7300

ISSN 2198-7319 (electronic)

Research for Development

ISBN 978-3-031-53293-1

ISBN 978-3-031-53294-8 (eBook)

<https://doi.org/10.1007/978-3-031-53294-8>

Politecnico di Milano

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# Chapter 11

## Dealing with Medicines Through Online Platforms and Communities



Carlo Emilio Standoli and Umberto Tolino

**Abstract** This chapter focuses on the link between social media and human health and well-being, with a peculiar interest in the communication of medicine, understood both as an object for treatment and as a commercial product. After an overview of social media and the extent to which they have changed access to the web, the way we create and disseminate content—personal or professional—and communicate with other people, the chapter analyses their contribution and use in medicine. Through observation of the trends on several social media, such as forums, blogs, and social networks, the chapter presents an analysis of the role of medicine in such environment, starting with the norms that regulate their communication and ending with the identification of platforms, channels, actors involved, modes of interaction, and registers of dialogue. Finally, the chapter proposes some reflections on how design culture can intervene in the relationship between medicines and social media, from the definition of guidelines for communication to research for improving the user experience of medicines.

### 11.1 The Use of Social Media and the Relationship with Healthcare

Today, around 65% of people worldwide have Internet access (Starri 2023). People spend an average of more than 6 h daily connected between websites, forums, social networks, gaming platforms, and other platforms (Starri 2023). Improved infrastructure and technology are crucial in this global spread and increase of Internet access. For instance, the development and adoption of mobile devices have enabled massive access to the network, both geographically and demographically. In this, the paradigm shift between Web 1.0 and 2.0 has also contributed, meaning the possibility for users with access to the web to create communities and content, share

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information, thoughts, personal messages, images, and videos, and even collaborate in real-time: people are now connected in a web-based world without borders (Farsi et al. 2022). Social media embody this paradigm shift of active and participatory web use.

According to the Merriam-Webster dictionary, *Social Media* can be defined as “forms of electronic communication (such as websites for social networking and microblogging) through which users create online communities to share information, ideas, personal messages, and other content (such as videos)” (Merriam-Webster 2023). Thus, social media includes sites, blogs and forums, for content creation and sharing, video creation and sharing, and social networks, etc. In the creation and spreading of content on the web, social media enable the creation of bottom-up content, in other words, by network users without specific programming knowledge, and sometimes without actually being experts in the topic of discussion; content can range from the professional dimension to the expression of personal thought, through micro-blogging, to the sharing of one’s own experiences, through forums or social networks, to the creation of encyclopaedic entries, etc.

Social media can thus be grouped into categories according to their purpose (Ventola 2014), that is:

- to aggregate knowledge and information (e.g., Wikipedia, GitHub, etc.);
- to create and share content (e.g., blogs and micro-blogs, such as Reddit, Twitter—X, etc.)
- to create and share media (e.g., YouTube, TikTok, Snapchat, etc.)
- for networking, whether professional (e.g., LinkedIn, etc.) or personal (e.g., Facebook, Instagram, etc.)
- for sending instant messages (e.g., Whatsapp, Messenger, Telegram, etc.)
- to play games in synchronous or asynchronous mode
- to sell, buy or exchange products and objects, etc.

In recent years, among the possible uses, social media tools have been used to promote health, both on one’s own and in society. Social Media can enable public information sharing, including in the health field, creating a communicative and collaborative atmosphere between everyday users, patients, medical and health personnel, and health and governmental structures. Social media tools can be useful to shorten the distance between patients and medical and health personnel, increase health literacy, or promote healthy lifestyles among different communities. By 2017, representatives of the World Health Organization (WHO) were already highlighting all the advantages and benefits that the intersection between public health understood in its traditional dimension and electronic and mobile health (e-Health, m-Health) would guarantee shortly (Steffelson et al. 2020).

As an essential tool in the health field, social media involves all the stakeholders, from health care providers to patients, from manufacturers of health care products to national and supranational organisations.

Depending on the different users, social media can find different application areas. For example, for physicians and healthcare institutions, social media can be used to present and share the results of biomedical research, reducing the barriers

between professionals through immediate contacts compared to those obtained through scientific dissemination and publication. Or, again, in the case of physicians and national and supranational governmental bodies, to communicate good practices for maintaining or monitoring one's health status to the general public. Or to be used for training young doctors by creating and disseminating content for new forms of formal and informal learning (Farsi 2021). Or offer telemedicine services and direct support to people. Over the years, for example, the WHO has organised structured communication activities through the leading social media and created a webpage (i.e., WHO MythBusters) specifically to counter all the unreliable and sometimes conspiratorial information that crowds the web and social media.

If viewed from the perspective of companies that produce and trade products and services for people's health and wellbeing, social media provides a showcase for connecting with different audiences. For example, social media for professional networking can be used to communicate one's research and product development activities to specialist and industry audiences or for recruitment campaigns. Social media for non-professional networking can be used to communicate one's values and corporate vision to a more generalist audience and promote messages to raise awareness of one's health status. In some cases, depending on country regulations, social media can also be used to market one's product range.

If viewed from the patient's perspective, social media can be used in different dynamics, such as top-down, bottom-up and peer-to-peer directions. In the first case, this includes all telemedicine or counselling services, in which the person can benefit from remote monitoring and dialogue with his or her physician or caregiver, allowing for the spreading of care and a significant reduction in time and costs. From this perspective, telemedicine is not intended to be the only service for personal care. However, rather than support for the traditional medical service, it comprises dialogue and direct contact with the physician—such as visual, auditory, tactile, emotional, and empathic. This also includes all actions and activities by healthcare providers to disseminate messages and information for health literacy, influencing the achievement of better behaviour through social reinforcement (George et al. 2013). The second case includes the use of social media platforms and social media that allow the person to find a health care provider—understood as both medical staff and hospital facility—appropriate to the expectations of care (Nayak and Linkov 2019). Indeed, social media represents the new word of mouth, where people can find all the information, they need to choose their preferred care pathway or doctor. At the same time, a person with low health literacy and the increasingly rapid dissemination of medical information—sometimes produced by sources that are not accurate or precise—can create confusion and produce risky behaviours that can damage health. In the third case, peer-to-peer interaction dynamics through social media are used to share information about therapies and treatments, drugs and dosages, doctors and hospital facilities, or to find support from people with whom one shares a health condition (Farsi et al. 2022). This is the case with portals and blogs such as PatientsLikeMe or DiabetesMine, where people-patients can discuss and find support from those with whom they share the same health condition. For example, in the Italian context, a representative case of the use

of social media in a health context and with a peer-to-peer dynamic is the initiative led by Salvatore Iaconesi. In 2012, after he was diagnosed with a brain tumour, Iaconesi started the “*La Cura*” project, making his medical records available online to deal with his illness openly. Over the years, he has been able to engage with doctors, neuroscientists, artists, engineers, designers, and ordinary people, approaching the disease from different points of view (Iaconesi and Persico 2016), not only seeking medical advice for his recovery but also developing new ways of communicating, interacting, accepting and coping with his illness and state of health.

Or, again by way of example, it is worth mentioning the role of social media during the Covid-19 pandemic, which was prominent in the dissemination of information, whether to tell what was happening in different countries around the world, to promote virtuous behaviour or share tools and solutions to support treatment, or simply to work remotely or meet loved ones from one’s home context. In this regard, an example of the positive use of social media is the experience of Cristian Fracassi, Dr. Renato Favero and the Isinnova team. At the beginning of the first lockdown, to cope with the shortage of intensive care supplies, through contacts via social networks, they re-designed charlotte valves to be adapted to snorkelling masks in order to use respirators; later on, they disseminated the project files, making their invention free to use, so that it could be produced and modified wherever it was needed (Redazione Open Innovation 2020).

However, there are not only positive cases and experiences in using social media regarding health. Again, during the Covid19 pandemic, it happened that many non-expert users, sometimes with a large following of followers, discussed or commented on medical phenomena, including vaccination, making negative judgments without having any element, suitable or knowledge to do so (Pershad et al. 2018). Or, as in the case of the Zika pandemic, studies have shown that at least 12% of the information on social networks such as Facebook was false, misleading and linked to conspiracy theories (Sharma et al. 2017).

Social networks often turn into an ‘echo chamber of ideas’, where biased and unsubstantiated opinions or points of view have greater resonance than evidence-based facts—not only scientific ones—due to the ease of sharing and dissemination without understanding the content, critical thinking (Weissmann 2012).

Another very recent example of the use of social media in health, and specifically in the use of drugs, is that of Ozempic. This medicine was developed to support treating people with type 2 diabetes mellitus. Its active ingredient stimulates insulin production and, among other effects, contributes to the feeling of satiety by inhibiting appetite (Couzin-Frankel 2023). This second effect was observed during clinical trials, and the manufacturer has considered the possibility of using the drug to treat obesity (Couzin-Frankel 2023).

Between 2021 and 2022, the medicine was then authorised for treating obesity in the United States and the European Union. Starting in 2023, however, the medicine started to be increasingly present on social networks, as it was used by non-obese people to lose weight without diets or physical activity (Mullin 2023; Menietti and Mautino 2023). Many videos have also circulated on platforms such as TikTok, testifying to the before and after use of the medicine. This strong diffusion and

interest in the medicine's 'benefits' has led to a substantial increase in the demand for it, often also outside the official channels, as understood from a prescriptive (i.e., the doctor prescribing the drug to the patient because he or she suffers from the disease) and legislative (e.g., the drug being sold through non-legal channels) point of view (Menietti and Mautino 2023). Therefore, this behaviour caused a decrease in the availability of the medicine for those who needed it, such as people with type 2 diabetes mellitus. Therefore, in all these cases, it is possible to see how the use of social networks can hurt people's health—even at a widespread and global level—due to the creation and sharing of content that, for example, questions medical culture without having a scientific basis and evidence, or that encourages bad behaviour.

Therefore, we must consider that social media allows new forms and dynamics of communication even in the world of health and personal care, where an exchange of information of any nature and structure occurs, from personal opinion to scientific evidence. To understand this phenomenon and to understand precisely how medicines and dialogues around the pharmaceutical world were present in social media, qualitative research was carried out on the main sites, forums and social networks used in different ways by pharmaceutical companies, doctors and health professionals, pharmacists, patients and caregivers. This research mainly examines the Italian context, both from a legislative and regulatory point of view and in content creation.

## 11.2 Medicines on the Web: From Advertising to Peer-to-Peer Dialogue

As addressed in other chapters of this book, the medicine can be considered as a product system composed of multiple levels, starting from the form (e.g., solid, liquid, etc.) defined to make the medicine more effective or based on business optimisation logics, or even to favour its consumption; to the different packaging (e.g., primary and secondary) to contain, protect, distribute, sell and store the medicine, or to communicate and make it recognisable; to the package leaflet, to support and guide the use process. Over the years, in addition to its role as a tool for preserving and maintaining the health of the person and the patient, the medicine has evolved into a true commodity designed for customers.

Some medicines, namely self-medication (over the counter—OTC) and non-prescription medicines (*senza obbligo di prescrizione*—SOP) are subject to the logic of any other type of commodity, from advertising and promotion in traditional and new media to distribution channels. These medicines have gone from being used exclusively for treatment, therapy or preventive purposes, to products to be consumed. For example, in the Italian context, as well as in pharmacies, the medicine can be sold in parapharmacies and through their own physical outlets or Internet sites. In this case, online sales are only allowed to authorised entities recognised by the Ministry of Health, and using intermediary websites or marketplaces such as Amazon or Ebay is prohibited. Both pharmacies and parapharmacies retain their

role as health care providers, where a person/patient can turn to a pharmacist to manage pharmacological therapy (e.g., from choosing the medicine to the interaction between medicines, from adherence support to pharmacovigilance).

However, entering these spaces—physical or virtual—the advertising of OTC and SOP medicines becomes evident, from display banners to promotions and discounts, as is the case for any other merchandise within the logic of large-scale distribution. With legislative decree 219/2006, the Italian Ministry of Health defined the fundamental principles, limits, characteristics, and content—acceptable and not—to manage the commodification and regulate the advertising of OTC and SOP medicines (Ministero della Salute 2006). Through the publication of the guidelines on health advertising of OTC and SOP medicines, the Ministry of Health regulated the presence of medicines in traditional broadcast media (e.g. newspapers, television, radio, websites) and social media, provided that the advertising message is authorised (Ministero della Salute 2023). The Ministry of Health must authorise any form of official presentation of medicines through the different media. This also applies to institutional-company websites if the medicine is presented or advertised.

Regarding advertising medicines in social networks, apart from the platform used, the Ministry of Health defines some essential characteristics of the advertising message. For example:

- the social network must technically enable all features concerning ‘comments’ and reactions (e.g., public likes, emoticons) to be disabled, and the ‘sharing’ function must also be disabled; and, where this is not technically possible, all messages disseminated on social channels must contain the following disclaimer: ‘The Ministry of Health only authorises the content of the advertising message. Any comments are the sole responsibility of the user, the company disassociates itself from user comments’;
- it is permitted to include in authorised advertising messages disseminated via social pages/profiles links that are activated in the following cases
  - links referring to websites and/or social pages/profiles containing promotional material already authorised by the Ministry;
  - links referring to content aimed at the public that does not require ministerial authorisation (e.g. containing health education information, self-medication, etc.).

In both cases, the company in charge of the material on the network will warn the user with the following wording: ‘*You are leaving the site (insert name) containing promotional material authorised under current health advertising legislation*’.

- links to other content aimed at the public (including in foreign languages), which requires ministerial authorisation and has not been obtained, are not permitted.—In the application for authorisation, the applicant must indicate the sites and social pages/profiles to which reference is made, if they are not explicitly mentioned in the message (e.g., ‘Find out more’ button) (Ministero della Salute 2023)

For different social networks covered by the guidelines (e.g., Facebook, Instagram, YouTube, TikTok, etc.), the Ministry defines specific rules regarding the use of posts containing text and image galleries, image and video carousels, stories or others. For example, it defines the maximum amount of posts that can be published (e.g., each company can submit to the Ministry for approval a total editorial plan containing a maximum of ten posts, of which a maximum of three are videos), or the length of the texts (e.g., each post cannot contain more than 70 words), or the possibility of sharing (valid only for YouTube).

However, these guidelines only concern companies that carry out specific advertising messages, while the actions of other actors, such as influencers—of various kinds—who use social networks to promote products or services, or patient networks, in which people share their experience with such a doctor or medicine, are not regulated.

For instance, in Italy, there is still no specific regulation regarding communication between doctors or between doctors and patients through social media. In the case of professional sites, such as those providing telemedicine services or where it is possible to book examinations (e.g. MioDottore.it, Medicitalia.it, etc.), the dialogue between doctor and patient falls within the dimension of healthcare practice. In the case of social networks, the situation is different. The scientific community predominantly agrees with considering these channels favourably and their use in communicating with patients and the population to convey correct information, combat misinformation, and promote public health. As there is no common regulation or guidance from the ministries, the different professional orders have tried to define recommendations for using social networks. For example, in July 2023, the Italian National Federation of the Associations of Physicians, Surgeons and Dentists (*Federazione Nazionale degli Ordini dei Medici Chirurghi e degli Odontoiatri*—FNOMCeO) drew up recommendations on the use of social networks, covering topics such as data confidentiality, handling friendship requests from patients, creating multiple profiles (i.e., personal and professional), the declaration of possible conflicts of interest (e.g., reporting whether the content of a post is funded or sponsored by a company), and the fight against disinformation and fake news (Santoro et al. 2023).

The Italian Federation of National Associations of Nursing Professions (*Federazione Nazionale Ordini Professioni Infermieristiche*—FNOPI) has also published recommendations on the use of social networks addressed to Italian nurses—citing the title of Marshall McLuhan’s work, the medium is the message—, to sensitise them to reflect on the nature of the content published, the different communication channels used, and the potential impact on the different communities. The fallout of a wrong—or misinterpreted—message can indeed negatively affect the individual and the entire professional community, from an ethical, deontological, cultural level (FNOPI 2019).

On the other hand, the Italian Federation of Pharmacists Orders (*Federazione Ordini dei Farmacisti Italiani*—FOFI) sent a communication to all national pharmacist orders, pointing out the presence of some people who, with profiles on Instagram or TikTok and presenting themselves as pharmacists, express evaluations

and dispense recommendations on the use of medicines, whether SOP, OTC or prescription drugs (Mandelli and Pace 2023). FOFI points out that this practice is contrary to the Pharmacists' Code of Ethics, and emphasises that advertising for medicines on social networks must be authorised by the Ministry (Mandelli and Pace 2023).

Conversely, the dialogue and exchange of information among patients is not subject to regulation or standardisation—other than that defined arbitrarily by the managers of the site, forum or blog, according to their own cultural, ethical and moral principles. As mentioned, social media are the new word of mouth of health, where users exchange advice on medicines, therapies, diagnoses, treatments, doctor's skills, sometimes without scientific evidence or objectifying experiences. For example, a phenomenon that occurred during the Covid19 pandemic emergency is that of *infodemia*, or the excessive search for and dissemination of information, including false and misleading information, in digital and physical environments that causes citizen-patients to engage in confusion and risky behaviour that can harm health (WHO 2023). Social media all enable the creation of content and the continuous search for immediate solutions: in the dynamics of information sharing between people/patients, where this is self-produced based on the individual's experiences and beliefs, virtuous cases coexist (e.g., PatientsLikeMe, DiabetesMine, MyPersonalTrainer, etc.) with cases that can contribute in creating misinformation.

### **11.3 Social Media and Medicines: A Qualitative Observation on Online Pharmaceutical Communication**

To really understand how medicines and the dialogues around the pharmaceutical world are present in social media, a qualitative research was structured by identifying the main social media, such as sites, forums and social networks, where pharmaceutical companies, doctors and health professionals, pharmacists, patients and caregivers are present.

The qualitative research was conducted with an observation programme that lasted approximately 2 months, starting from the Italian context in consideration of the legislative and privacy constraints, as well as for a better understanding of the modalities and language adopted by the different users, for opportunities to understand the contents and the audience to which they were really addressed. At a second level, the different types of platforms under observation were identified. Amongst these, some institutional sites were selected (e.g., AIFA website), the sites of some pharmaceutical manufacturers, sites for services or consultancy (e.g., MioDottore, MyPersonalTrainer, etc.), forums and micro-blogging platforms, which group together people with shared interests and which deal with the subject of health, and finally some social networks (e.g., Instagram, TikTok, etc.).

A number of representative profiles of the different categories (e.g. companies, physicians, pharmacists, patients and caregivers) were then isolated, in the guise of



content-creators or influencers, and of recipients of the information created (e.g. those who search for drug package leaflets or those who comment on the content-creators' posts). For these, observation summary sheets were produced, and a mapping of the themes, processes, and dynamics of interaction was carried out, which changed both due to the platform used and the directionality of the communication itself. For example, in some cases, it was analysed how communication can go from being one-way and institutional, typical of companies that produce drugs or of sites offering assistance and support for treatment (where brief exchanges may take place in the case of areas intended for communication between doctors and patients), to two-way communication (typical of content creators on social platforms) or peer-to-peer (typical of forums and blogs used by patient networks). Another variable observed is the temporality of the interaction, both in terms of the duration of the exchange or the content produced and the synchronicity or asynchronicity of the dialogue (e.g., likes on Instagram live or comments on posts).

A series of contents/posts were then selected, organised by circulation and popularity, based on the number of visits and interactions with the target audience. For some sites and forums, an analysis was also made concerning accesses and consultations occurring monthly, considering the duration of access, gender and age group of the population.

The objective of this qualitative research was to map the experience that the user, interested in medicines or, more generally, in health, may have while browsing, trying to highlight the modalities, recurrences, good practices and criticalities during interactions. In this way, it is possible to map out areas of interest for future project interventions aimed at communication or process innovation relating to the presence of medicines in social media. By choice, this mapping did not examine the presence of medicines on the dark web.

### ***11.3.1 Top-Down Communication on Social Media: Medicine Communication by Organisations, Institutions and Companies***

As mentioned in the previous paragraphs, the Italian Ministry of Health has established guidelines for online communication in the health field, defining recommendations and limitations regarding the presence of medicines on social media, with a specific focus on advertising and marketing actions. Nevertheless, medicines are highly present on the web, considering the frequency of use of the leading search engines to obtain information on specific diseases and related pharmacological therapies, as well as the dosage and effects of medicines. The medical and pharmaceutical-related offers is extremely varied and vast, both in terms of numbers and type of service: from medical-scientific information sites, such as the Ministry of Health or the Italian Medicines Agency (*Agenzia Italiana del Farmaco*—AIFA), to forums for direct online consultation—subject to certified access -, to sites offering databases

of package leaflets, to sites and company profiles, blogs, Facebook groups, or profiles on social networks where this issue is addressed from different angles and perspectives (e.g. doctor, pharmacist, patient, caregiver, caregiver, etc.), physician, pharmacist, patient, caregiver, expert or non-expert, etc.).

On the official websites of agencies and institutions such as the Ministry of Health and AIFA, health information is treated in a technical-scientific language, given their regulatory role in managing medicines development, use, adoption and management processes. Above all, AIFA is the national authority responsible for medicines regulatory activity in Italy, in permanent dialogue with all specific stakeholders, from pharmaceutical companies, to the medical-scientific world, to patients' and patients' associations. In parallel to its website, where official reports on medicines, guidelines, scientific articles, etc. are published, AIFA has created several profiles on social networks (e.g., Instagram, Twitter-X), which proposes informative content tailored to the audience of these platforms. The content can range from managing medicines in the home or during the different seasons, to the correct disposal of medicines, the differentiation between branded and equivalent medicines, and the correct use of antibiotics. The intent is informative and educational, not to advertise the use of a given medicine. AIFA has also created a podcast covering the same topics. Unlike the website, in the discourse on medicines through social networks, AIFA adopts a language—verbal and enriched with images, as in the case of Instagram—that is relatively simple but includes medical-scientific terminology, intending to increase medical-pharmaceutical literacy among the population.

However, medicine is present in many different ways, both in various containers and on social media. As mentioned, on some platforms and sites, the package leaflets of different medicines are reproduced. These can then be searched and consulted online, like a medical-pharmacological breviary; these databases and handbooks are accessible both from the web and apps on the main markets. The user can then consult the dosage of the medicine, with all the risks associated with the processes of self-diagnosis and self-medication. It is precisely for this reason that in almost all of these sites and apps, a repeated formula invites one to refer to the physician for a correct definition of pharmaceutical therapy, to avoid the temptation and risks related to self-diagnosis and self-medication.

The medicine is also dealt with on sites and platforms offering medical consultancy services (e.g., MioDottore.it, MedicItalia, ABC Salute, etc.), which can be distinguished between those that propose a divulgative and scientific information action and then arrange a visit at the doctor's office, and those that propose the sale of services and consultancy directly on the platform, without an in-person visit. In the second case, it is easy to witness dialogues between a patient—generally situational and inexperienced, and made anonymous on the platform for other readers—who requests a consultation, and then waits for a response from the various doctors. Within 24 h, one can see replies from medical specialists who answer the question expressed in a clear though not exhaustive manner, referring one to a private—and paid—consultation via the platform itself. The user is then free to refer to one or none of the responding doctors. In these dialogues, the medicine is often quoted, from an already defined therapy, from hearsay therapies, or a prescription is

requested. In these forums and especially in public exchanges, it is not permitted to advertise, prescribe or dose a drug without an examination or exchange of medical records or examinations.

Over the last few years, pharmaceutical companies have been using social media for different communication actions, from their mission and vision to their research and testing activities, to promoting healthy lifestyles. While having a website has been the main form of web presence aimed at the general public for years, pharmaceutical companies have only recently adopted their official pages on social networks (e.g. LinkedIn, Facebook, Instagram, Youtube, Twitter—X). The content on these platforms is mainly editorial, such as scientific articles, conference proceedings, participation in events and round tables, and graphic posts celebrating international days for preventing or combating a disease. The aim is to inform and raise awareness among the public through graphic and photographic posts and videos, in which company employees are sometimes present. The presence and use of the employee's testimony is conveyed to bring the company itself closer to the public and users: these are often stories that deal with scientific topics, with a communicative register that the public can use and an emotional character. For example, a company operating in the diabetes pharmaceuticals sector uses its social networks to give the floor to employees/patients, who testify about their relationship and living with the disease, also offering suggestions on how to deal with everyday life, in order to have a healthier life and a better relationship with the treatment processes. Another company, on the other hand, has created a column addressing the theme of 'word of mouth' on the web: starting from a news item or post that has gone viral on the web and which deals with health-related issues or the creation, use or management of a medicine, it attempts to address the theme of false or misleading information, presenting qualitative data and authoritative sources, using popular language and sometimes an ironic tone.

Sometimes, through social networks, companies make use of posts containing questions or surveys to start a series of posts in which the given topic is discussed and users' questions are answered, always within the limits of what is defined by the relevant standards and legislation. Also widespread in the feeds of these companies is the use of stories, such as posts about medicines of the past, stories and anecdotes about the inventors of a given medicine that revolutionised treatment processes, etc. The language used is very often scientific, informative, and explanatory.

### ***11.3.2 Bottom-Up and Peer-to-Peer Communication on Social Media: The Cases of Med-, Pharma-, and Patient-Influencers***

In recent years, social media influencers have assumed a significant and impactful strategic communicative role in extremely heterogeneous sectors, such as entertainment, fashion, food, travel, etc., capable of directly reaching and engaging

consumers (Willis and Delbaere 2022). Social media influencers can be defined as ‘third-party users of social media who have achieved micro-celebrity status in the form of large followings on social media platforms and who have a position of influence in their audience’ (Delbaere et al. 2021). In the paradigm shift between selling a product and promoting a lifestyle, for companies, social media influencers represent a channel for communication, positioning and enhancing their offer. In fact, compared to traditional merchandise communication channels, social media influencers can reach consumers more quickly as they can recognise themselves in influencers, aspire to such lifestyles and consumption, or have passions or interests in common. It is precisely in the case of communities with common interests, knowledge, skills, or experiences, which often cannot be artificially replicated, that the spread of health influencers, such as med-, pharma- and patient- influencers, lies.

Med-influencers and pharma-influencers are physicians and pharmacists, trained and experienced personnel with an active presence on social networks, who share content in a structured and conscious manner and are recognised as a reference by a community of followers. Med- and pharma-influencers can vary their language and the way in which their messages are presented, using professional or ironic informative modes: the message is always correctly conveyed, avoiding creating ambiguous or even false and tendentious information. For example, in social networks such as TikTok, med- and pharma-influencers mainly create videos in which the language is light and friendly, using gags and dances. In other cases, like some Instagram posts, a more informative and discursive mode may be adopted, conveyed through image carousels or short reels. In both cases, the aim is to inform using modalities and languages that are accessible to heterogeneous audiences in terms of age, education, pathologies, interests, etc., creating short and easy-to-use content to explain symptoms, dosage, management, storage and interaction of medicines. In some cases, med- and pharma- influencers give space to user insights and requests through direct interaction (Instagram Directs) or through posts and comments.

As indicated by the standard, under no circumstances may med- or pharma-influencers give commercial indications or include drugs of specific companies in their content, limiting themselves to advising on active ingredients of over-the-counter medicines concerning specific diseases.

As far as patient-influencers are concerned, they are actively involved in online communities where they share personal experiences with the disease and the care processes, from therapy management to the relationship with doctors. In the most virtuous cases, this exchange of experiences can help in the literacy and self-management of the care process (Willis and Delbaere 2022). Among the patient-influencers, we can identify patient advocates, third-party users of social media who speak out to raise awareness about diseases and illnesses. They are a specialised social media influencer and, in contexts where this is possible, such as in the United States and for specific types of drugs, are recruited by pharmaceutical companies to participate in developing and promoting pharmaceutical products (Willis and Delbaere 2022). While the presence and dissemination of these influencers may help overcome the stigma of certain diseases (Rosen et al. 2024) or contribute to greater literacy concerning the medicine and the treatment process, the lack of

medical education and training concerning witnessing a treatment-disease experience may present the risk of conveying ambiguous information to a broad audience. In this regard, we can cite the already presented case of the abuse of Ozempic (Menietti and Mautino 2023) or Kardashian's experience with the Diclegis: to treat her morning sickness, the influencer used such medicine during her pregnancy and did not hesitate to communicate to her followers the benefits obtained from the use of the drug with a post in which she showed and commented on the drug. In doing so, she violated FDA regulations on drug advertising, conveying possible risky behaviour in using and handling medicines (Hauser 2015).

## 11.4 Possible Design-Oriented Intervention Scenarios to Enhance the Dialogue on Medicines in Social Media

The opportunity to access the internet, the spread of social media, the possibility to create and share information through different channels and modalities is changing the relationship between people and consumer products, also in the specific case of medicines. The entire pharmaceutical management process—from development to marketing, thanks to data mining and the observation of people's behaviour and preferences on social media—to the choice and use of medicines—advertising and word of mouth influence the orientation and purchase choice of the drug, think of the difference between branded and equivalent medicines -, up to the preservation and disposal processes, is influenced by the advent of social media. Even if from a legislative and regulatory point of view, and here we refer to the Italian context, it is not possible to market OTC and SOP medicines directly through social media there are already websites and apps offering the service, which in turn have institutional profiles in the main social platforms. In this context, what contribution can design culture make?

At a first level, design culture could intervene in redesigning certain elements accompanying the medicine, such as packaging. This is the first real means of contact and access to the medicine and information on the medicine, making it a real node in a connected system of tangible and intangible objects and stakeholders in the process of production, use and disposal of the medicine.

A second level concerns the use of social media as a tool for research and analysis, to understand the real points of view, needs, and requirements of the communities of interest with respect to the medicine, in its dimension as an object for treatment that has not yet fully surpassed the dimension of the sole—albeit indispensable—dimension of functionality: a medicine 'works' because it helps the person, the body, to deal with an adverse situation. But as it becomes an object, it must also relate to other needs and necessities. In its extended form, the medicine is also packaging, designed more to protect and preserve the active ingredient than to facilitate use. The medicine is also form, in its various declinations: it can be ingested, injected, smeared, inhaled, and how many of these forms are designed as much for the functionality of the cure as for the process, the acceptability, the accessibility of the cure. The medicine is also process and management of the different phases of

storage, use and disposal. Actions of data mining and observation through social media and the involvement of communities of interest, if also interpreted through the culture of the project, could make medicine evolve from the functional dimension to that of use, acceptance, and autonomy of care.

A third level relates to the definition of new service platforms in which the digitalisation of information and the creation of digital twins is accompanied by information on the purchase and use of the medicine and the data conveyed through social media. It could represent a lever for better profiling of the subject and for the development of personalised, participatory and predictive care, while considering the limits imposed by privacy and the ethics of data use.

At a further level, the design culture could translate and make even more accessible all those communities of interest related to the theme of medicine, care and health: the dynamics of communication, involvement, interaction, dialogue, and imitation, taken from the social media world and translated into more health-oriented media, in which the active and participatory involvement of knowledge and care experiences serve to create structured, faithful and supportive information for interactions between widespread communities.

These are just some of the trajectories that design culture could intercept through social media concerning the evolution of the medicine in its dimension of object and node within the care system.

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