The Patient Journey

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10.1 Introduction

Almost 20 years after publication “To Err is Human: Building a Better Health System” (Kohn et al. 1999), patient safety is still not widely implemented. This report from the Institute of Medicine is the milestone that constituted a turning point for improving quality of care and patient safety identifying the need to rethink healthcare delivery to provide safe, effective, and efficient care.

The barriers of implementing patient safety as a driving force for change towards more effective healthcare include multiple factors: insufficient involvement of all stakeholders contributing to the care process, lack of willingness of organizations and individuals to learn from errors and scarce investments in patient safety improvement and research.

There is a growing need to promote systems approaches to finding solutions in healthcare to improve the safety of care, the quality of healthcare delivery, patients’ health and citizens’ well-being.

The discussion paper “Bringing a Systems Approach to Health” defines the systems approach as one “that applies scientific insights to understand the elements that influence health outcomes; models the relationships between those elements; and alters design, processes, or policies based on the resultant knowledge in order to produce better health at lower cost” [1].

A multidisciplinary approach must include the involvement of citizens and patients as fundamental contributors to the design, implementation, delivery, and evaluation of health services.

This means that citizen participation plays an essential role, bringing the unique point of view of patients and family members into the debate on patient safety and quality of care.

Patients and more generally citizens, when actively and systematically engaged, bring ideas and experiences which can support a collaborative and reciprocal learning process among the healthcare stakeholders. This produces knowledge that leads to improved practices, a real knowledge creation process where the dynamic participation of all actors in healthcare systems contribute to an active learning environment where the identification, the investigation, and the planning of solu-

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tions related to health incidents is a cyclic process enabling healthcare knowledge creation.

The added value of involving patients in healthcare is, respect to other more complex interventions, a low cost opportunity to take into consideration unconventional points of view creating and building knowledge and providing original insights and ideas that otherwise would not be considered.

Health professionals and patients' skills and knowledge are acquired through individual experience or education and transferred to the health organizations in a perspective of co-production of healthcare. It is a merging of the efforts of those who produce and those who use the solutions to address health problems. It serves to establish a strengthened and long-term relationship in terms of trust and effectiveness and to distribute the responsibilities among all stakeholders [2].

In light of these arguments, the systems approach—inspired by the fundamentals of ergonomics and human factors (HFE)—creates new alliances between healthcare and engineering, of which patient journey is a challenging example [3].

Applying the systems approach to patient safety allows the analysis of the factors that characterize the encounters and the interactions between healthcare professionals and patients during the entire course of care. The observation of possible critical issues to the individual and specific encounter between clinician and patient is crucial in widening the scope of observation and research of the entire "journey" of the patient, taking into consideration the complexity of patient, their values and needs, their preferences, the economic and social context in which they live, and language and communication issues.

These observations and research should be carried out considering the interconnections and interactions together with the components of the processes; importance should be given to the context, and to manage the complexity, the value of a holistic approach.

10.2 The Patient Journey

A modern health system looks to the future in the context of the challenges imposed by the real world. It must manage the gap between guidelines and health protocols and what effectively happens and how reality is perceived by patients and family members.

It is more and more necessary to bring the patient's point of view in the analysis of the care process, in the incident reporting and analysis, in the design and implementation of solutions and guidelines in healthcare.

Vincent and Amalberti in "Safer Healthcare" (2016) [4] stated that the incident analysis should broaden the class of events having consequences on patient safety. Incidents reported from the patient's point of view should be included in addition to those suggested by health professionals. Additionally, when analyzing an incident, it should be done in the context of the patient journey rather than a single episode.

Instead of focusing on the individual encounter, it is necessary to extend the observation timeframe by applying the examination of contributing factors to each of the encounters that compose the patient journey (temporal series of encounters with healthcare facilities, a hospital unit, a specialist visit, a primary care clinic, a home health agency), considering both the negative and positive events and the points for improvement that were revealed (Fig. 10.1).

The adoption of this wider approach is unique in that it incorporates the patient's perspective of safety and includes new features in the incident analysis such as asking patients to recount the episode of care, including patient and family in the investigation team when possible, asking patients the contributory factors from their point of observation and perception and involving patients and families in the reflections and comments on the disclosure process [4].

The episodes patients and families can highlight are often different from those that professionals are more accustomed to reporting. However, patients could be involved in further ways in incident reporting and assessment, and today patient-derived information constitutes a free and little used resource.

As per McCarthy's definition, "patient journey mapping describes the patient experience, including tasks within encounters, the emotional journey, the physical journey, and the various touch points" [5]. Carayon and Woldridge define "patient journey as the spatio-temporal

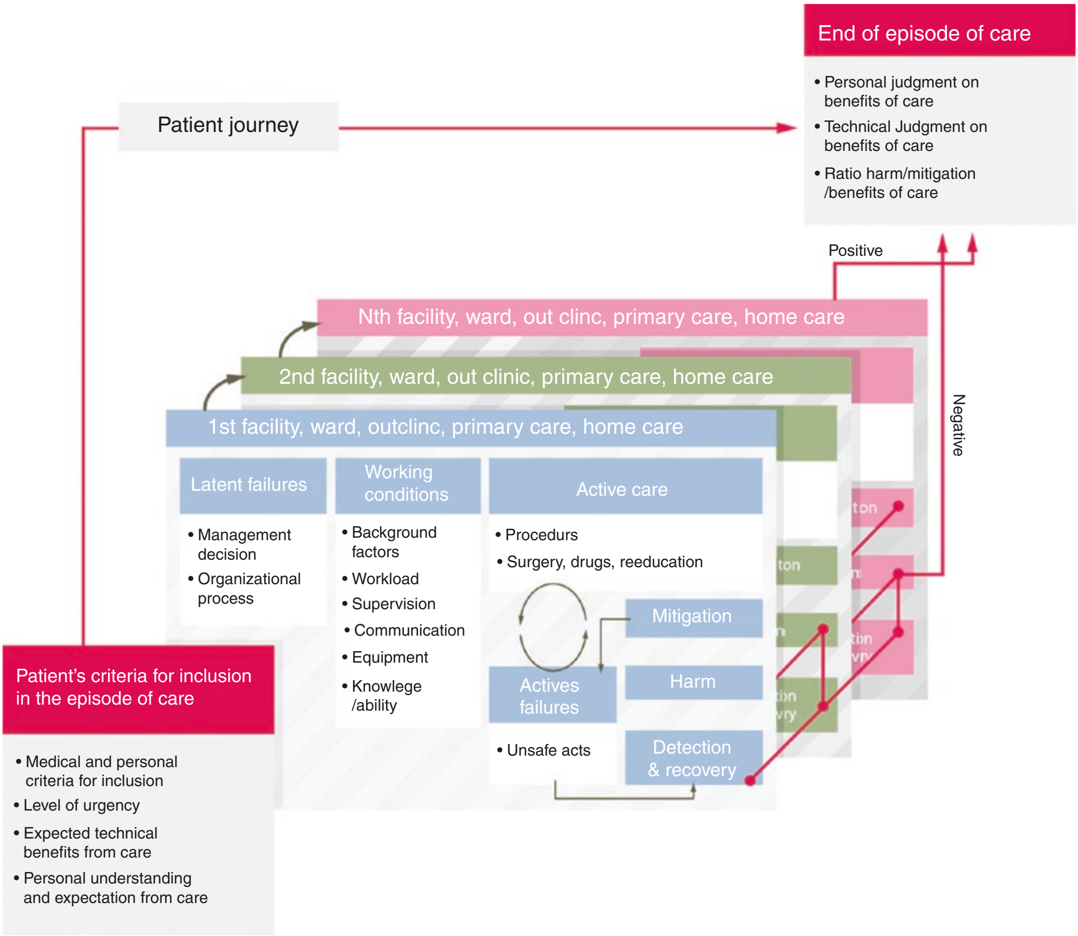

Fig. 10.1 Analysis of safety along the patient journey

distribution of patients' interactions with multiple care settings over time" [3], where at each point of touch with each healthcare service along the patient journey, the patient interacts with several system elements (task interaction, physical environment, interaction with tools and technologies, organization interaction, interaction with other organizations and other people, interaction with other people and teams within the organization) (Fig. 10.2).

The patient journey represents the time sequence of what happens to the patient, especially during transitions of care, in particular considering that the health professional who takes care of the patient only sees the portion of care for which he is responsible and in which he has an active role. Conversely, the patient is the only person who has a continuously active and first-hand role during their health journey. They alone are in possession of information that characterizes the entire care experience.

Moreover, when patients navigate their journey, they contact and interface with multiple work systems at several time points, where the sequence of interactions in the work systems determine the outcome experienced by patients and families, healthcare professionals, and health organizations. (Fig. 10.3). Each local work system is influenced by a wider socio-organizational context, which can be formal healthcare organization (such as hospital, primary care facility, nursing home) or informal (home).

Every point of the patient journey offers data on health outcomes and patient experience out-

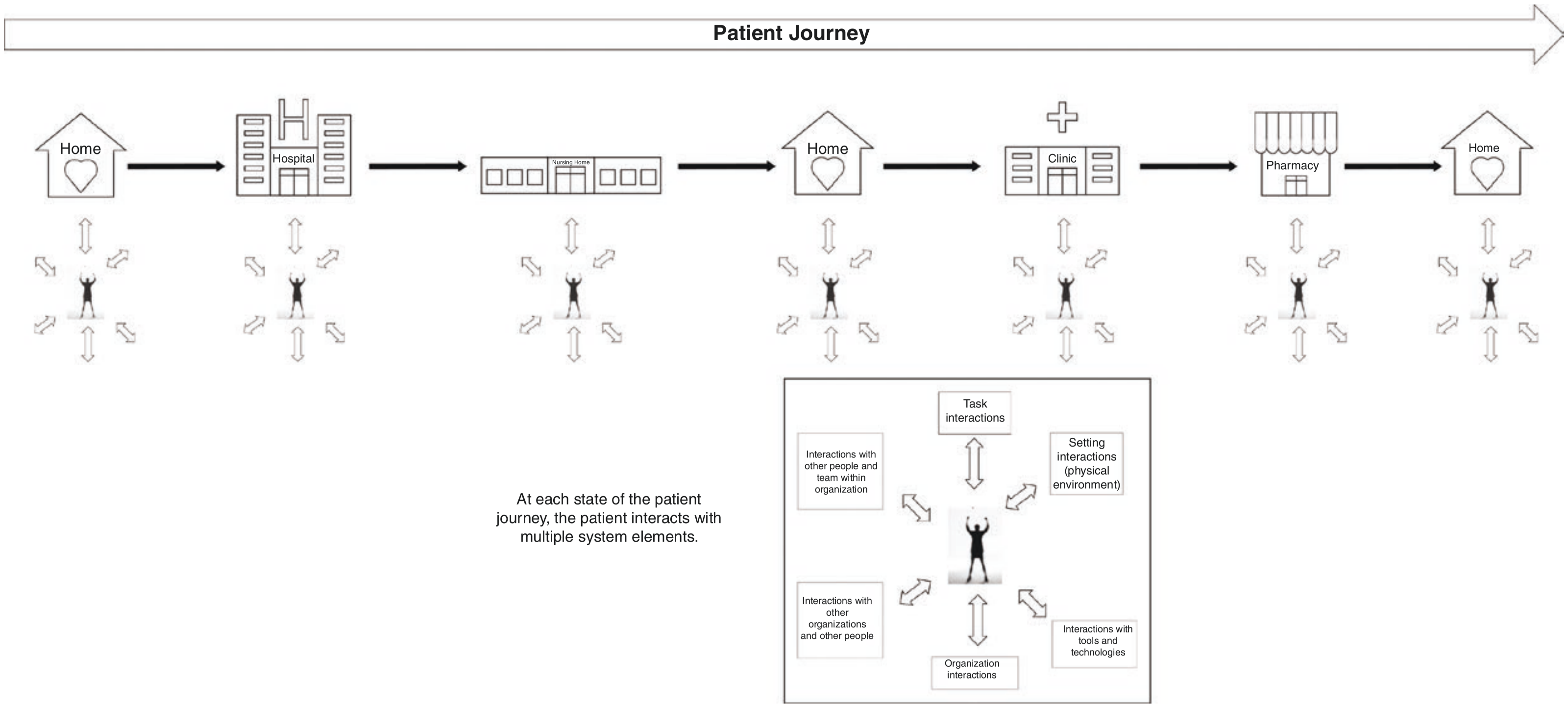

Fig. 10.2 The patient journey as a set of interactions and transitions

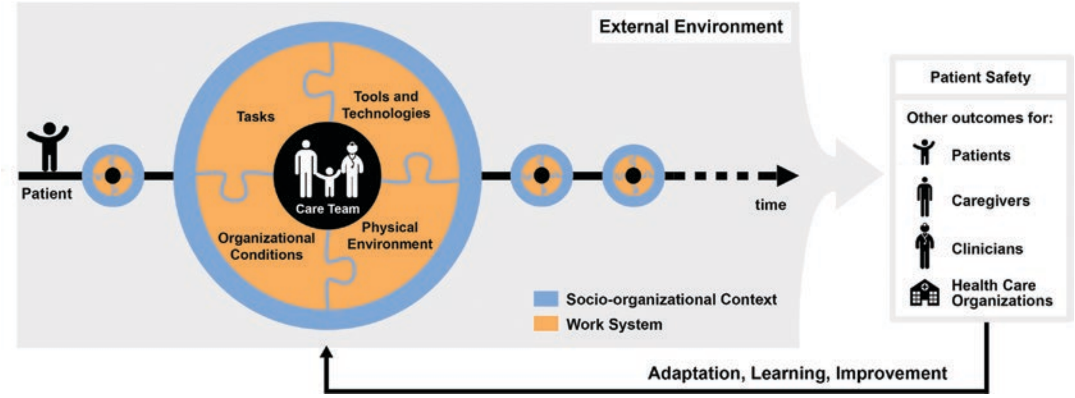

Fig. 10.3 SEIPS 3.0 model: sociotechnical systems approach to patient journey and patient safety

comes that should be used as feedback to redesign healthcare work systems in terms of adaptation, learning, improvement.

Patient's experience represents an important resource in participatory collaborative design, especially in the patient journey where this experience is the result of multiple interactions across space and time.

10.3 Contextualizing Patient Safety in the Patient Journey

Many of the incidents or near-misses during healthcare are not due to serious errors, but to the combination of small failures, such as limited experience of a recently qualified doctor, use of obsolete equipment, an infection difficult to diagnose or inadequate communication within a team.

We know that the analysis of an incident requires looking back to the succession of events that have occurred and that led to the problematic episode, considering both active and latent errors, and all the aspects connected directly or indirectly. It is fundamental to examine the safety of the entire patient journey, all the encounters that make up the entire care process, to study the whole medical history of the patient in an attempt to reconstruct all the elements that characterize the "health journey", not only from the viewpoint of the health professionals, but also from that of the patient and family.

In light of these arguments, new concepts, tools, models, and methods need to be embraced to support patient safety in the patient journey.

A significant contribution in terms of concepts, frameworks, and models is offered by Industrial and Systems Engineering, and often human factors and systems engineering (HF/SE) have an approach to include the preferences and the needs of stakeholders when designing solutions to address the critical aspects of a health process.

Human factors and ergonomics are described as "the scientific discipline concerned with the understanding of interactions among humans and other elements of a system, and the profession that applies theory, principles, data and methods to design in order to optimize human well-being and overall system performance. Practitioners of ergonomics and ergonomists contribute to the design and evaluation of tasks, jobs, products, environments and systems in order to make them compatible with the needs, abilities and limitations of people. Ergonomics helps harmonize things that interact with people in terms of people's needs, abilities and limitations" [6].

Process models have found widespread use in drug management, visit planning, care transition, to name a few, and can offer tools and methods to investigate interprofessional and physician–patient communication, interruptions and health information handover.

Drawing from the finding of Carayon's studies [3], the Systems Engineering Initiative for

Patient Safety (SEIPS) model gives a description of five work system elements which when applied to a definite patient journey model should outline who (person) is doing what (tasks) with tool and technologies, taking into consideration the physical and organizational environment where all these activities take place. All these factors have to be examined for both patients and workers and the process analysis and modelling have to consider what patients and families/caregivers, healthcare professionals and workers actually do (*work-as-done* versus *work-as-imaginated*).

Patients, families, and caregivers are deeply involved in the healthcare process due to the tasks they carry out in the intermediate sectors of care between encounters. Away from direct interactions with professionals, they have to perform multiple actions requiring understanding of what behaviour to adopt, which instructions to follow, how to administer a medication and how to communicate with hospital doctors, general practitioner, and home healthcare professionals [3].

Taking into account what has been highlighted so far, one of the leading and most challenging keys to success in improving patient safety is to adopt a systems approach to patient safety which includes the patient's perspective about their health journey throughout the time of care and across all the care settings.

This assumption highlights that patients and their families are valuable resources and can play an important role in patient safety improvement efforts. Viewing health systems as "co-producing systems", patients can engage as partners in co-producing patient safety improvement activities individually, in groups and collectively. Individual patient and family member participation/co-production of safer care is fundamental. Equally as important is the co-management and co-governance of healthcare services, in addition to the engagement of communities in policy definition and designing activities.

In fact, patient engagement directs the design of healthcare systems towards the preferences, the values, the real-life experiences, and—not less important—the skills of the people to enhance patient safety in the patient journey.

Such a change of perspective involves multiple dimensions of interactions and relationship between patients and professionals, encompassing cooperation, dialogue and listening, trust, reciprocity and peer-to-peer work [2].

It follows that on the one hand the healthcare organizations have to demonstrate the willingness to support health professionals to effectively engage patients in the patient journey to achieve the common goal of reducing the risk of patient harm or incidents as well as the willingness to integrate patients and family members as partners into quality and safety improvement efforts. On the other hand, it is necessary to motivate and encourage patients and families/caregivers to actively participate during the individual care process for safer care as well as partner in organizational patient safety improvement efforts to ensure safer care for others.

The working group *Patient and Family Involvement for the delivery of Safe and Quality Care* [7] stated that the utmost priority to realize the patient involvement is the training of patients, followed by the promotion of interdisciplinary training programmes for healthcare professionals to promote patient and family engagement, the implementation of multilevel structures that allow for participatory processes by patients and smarter allocation of resources in healthcare that supports involving citizens in patient safety improvement efforts for better healthcare.

This working group was part of the activities of the "1st International Meeting about Patient safety for new generations—Florence, 31st August and 1st September 2018" organized by the Centre for Clinical Risk Management and Patient Safety, Tuscany Region—WHO Collaborating Centre for in Human Factors and Communication for the Delivery of Safe and Quality care [7].

Therefore, training for both patients/families/advocates and health professionals is a pillar on which to build active engagement of patients and consequently an effective and efficient patient journey. From this perspective, the participation of patients (i.e. representatives of patients' associations and organizations, patient and citizen advocates) in training courses—specifically designed for this target audience of trainees and aimed to encourage co-production of care—is an essential and effective activity to co-produce a better healthcare system in terms of quality and safety of care.

Sharing a common language, promoting citizens' and patients' awareness of importance of co-production of care, teaching the key role that patients can play in making treatments safer (investments in health literacy), learning to work together and within a network (locally, regionally, and nationally/internationally) on priority safety and quality of care issues: these are some of the main strengths of training courses aimed to be at the basis of active engagement of patients and citizens.

Examples of successful training courses include "PartecipaSalute" and "Accademia del Cittadino" organized in Italy by Laboratory for Medical Research and Consumers Involvement of the Istituto di Ricerche Farmacologiche Mario Negri IRCCS and the Centre for Clinical Risk Management and Patient Safety, Tuscany Region. The following paragraph describes this educational experience which is specifically designed for citizens and patients to improve their knowledge and skills in patient safety and quality of care, with the aim of co-producing better healthcare services.

10.4 From PartecipaSalute to the Accademia del Cittadino: The Importance of Training Courses to Empower Patients

Over the last few years in the field of health and research and with regard to participation and involvement of citizens and patients, we have witnessed the transition from a paternalist to a partnership model. Individual citizens and those citizens involved in patients' associations or groups have acquired a new role: no longer passive but actively involved in decision-making regarding health, healthcare, and research in the health field [8, 9].

This is a progressive step-by-step process based on the recognition and implementation of the key concepts such as health literacy and empowerment. Health literacy, more properly used at individual level is defined as the capacity to obtain, read, understand, and use healthcare information in order to make appropriate health decisions and follow instructions for treatment [10]. Empowerment, more used at the community level, is a process that, starting from the acquisition of accurate knowledge and skills, enables groups to express their needs and more actively participate to request better assistance, care, and research. At this level, the availability of organized independent and evidence-based training courses is essential to allow people to be able to critically appraise and use information about the effects of healthcare interventions. Consequently, they will have the skills to participate in the multidisciplinary working groups (composed of researchers, health professionals, patient and citizen advocates, institutional representatives).

In the late 1990s, the Istituto di Ricerche Farmacologiche Mario Negri IRCCS held the first training courses of this kind focused at breast cancer associations. Some years later, within the project PartecipaSalute—a not-for-profit research project designed to foster a strategic alliance among healthcare professionals, patients, and their organizations—an ad hoc training programme for representatives of citizens' and patients' organizations was defined with a multimodule format [11, 12]. This was an innovative approach, at least in the Italian setting in that period.

PartecipaSalute training programme has combined different experiences: the Mario Negri Institute IRCCS experience in collaborative research activities with patients' associations, the Italian Cochrane Centre with the activities aimed at promoting the principles of evidence-based medicine, and Zadig long-term experience in health communication. The above promoters jointly developed the PartecipaSalute training programme on the belief that data are more important than opinions, and that every decision should be supported by well-conducted research data.

The spread of this belief to patients and citizens with the purpose of stronger involvement was a key point of PartecipaSalute training courses.

Therefore, patient, family, and community knowledge of the principles of how evidence is developed through clinical research is essential to make or support decisions in the health debate, to promote better clinical research, or to convey correct information. The strength of the PartecipaSalute programme was based on the exchange of experiences in an interactive way aimed at creating opportunities for discussion, overcoming the teacher–learner model. Each session started with an interactive discussion of a real situation—such as a screening, vaccination, therapy—and after sharing data, opinions or articles from media, evidence was presented and discussed, underlining significant methodological aspects. The programme offered the opportunity to debate the value and significance of the methodology offering critical appraisal tools. Each participant was invited to take an active part, starting from direct personal or associative experience. Table 10.1 presents the topics considered in the first three editions of the training programme. The participation was free, and different types of materials were provided including an ad hoc manual published by PartecipaSalute, copies of the PowerPoint presentation and articles.

Table 10.1 Topics considered in PartecipaSalute [4, 5] and PartecipaSalute-Accademia del Cittadino training courses

ABCs of clinical research
Aimed to offer conceptual and practical bases and technical tools to critically appraise the methodology of epidemiological/clinical research; to know and discuss relationships between ethics and clinical research, including participation on Ethics Committees.
Uncertainties in medicine
Aimed to discuss the probabilistic nature of the medical knowledge; to understand the intrinsic variability of the clinical practice; to deepen the relevance of values and preferences in medical decisions.
Conflicts of interest in medicine
Aimed to encourage critical awareness about conflicts of interest in medicine, in clinical research, and among citizens' and patients' associations; to discuss the impact of conflicts of interest on clinical practice and clinical research.
Health information
Aimed to present the strategies and methods behind the communication, in particular, related to marketing of drugs and devices; to coach a critical reading of medical and scientific literature, lay people articles, and mass media health campaigns.
Credibility and strength of consumers'/patients' associations
Aimed to discuss the requirements needed to raise the credibility of patients' associations; to identify the possible role of advocacy of patients' associations in healthcare.
Participate equally in multidisciplinary groups
Aimed to discuss the model, role, and activities of representatives of consumers and patients within the working groups evaluating feedback and results obtained.

Considering the characteristics of the programme and its modular structure, the PartecipaSalute training programme could be adapted to specific contexts. In fact, the experience of PartecipaSalute was adopted at the regional level by Regione Toscana (Centre for Clinical Risk Management and Patient Safety and the Quality of healthcare and Clinical pathways of Health Department, Tuscany Region) developing a more specific training programme called PartecipaSalute-Accademia del Cittadino (Academy of Citizen), focused on patient safety and risk management. In particular, after some modules on methods related to evidence-based medicine, uncertainties in medicine and information and communication in health, the training was mainly dedicated to regional and local activities on clinical risk management, the role of patients' associations to improve patient safety and to support the implementation of best practices, the analysis and data of adverse events and risk assessment in terms of quality and safety in the care processes (Table 10.2).

The PartecipaSalute-Accademia del Cittadino joint training programme has been implemented in three editions over the last decade and has trained about 100 members of patient and citizen advocates representing 38 patients' associations. The courses ranged from 5 to 3 modules of 2 days each in residential mode to allow participants to get to know each other and create a network of associations committed to be engaged in clinical research, quality, and healthcare safety issues.

Table 10.2 Topic integration in the PartecipaSalute-Accademia del Cittadino joint courses

Adverse events and safety of care Aimed to explain what are the adverse events in healthcare, how they arise, and how it can become an opportunity for improvement; methods to analyze incidents and near-miss events with the multidisciplinary approach of ergonomics and human factors; and what reporting and learning systems are and the role of patients in reporting medical error.
The new role of patients and citizens in the evaluation of quality and safety in the health system Aimed to help participants learn the best practices for patient safety and the accreditation system for quality and safety of care, to enable active participation in the co-design of the practices, the implementation, the evaluation, and the diffusion of safety solutions to make patient safety a reality.
The interpretation of health quality and safety data, the participation tools to empower patients and citizens in the healthcare experience Aimed to enable trainees how to identify complete and reliable data on the quality and patient safety, how to interpret them and what they are for. Which are the tools that patient and citizen associations can use to participate in the planning and assessment of healthcare.

The entire educational experience was characterized by the use of participatory training methods, based on working groups, practical exercises, lectures from experts with opportunities for discussions. As a result of this training course model, the participants were recognized as “expert patients” and were regularly involved in basic activities for promoting patient safety as auditors on significant events and helping to define policies on patient safety at the Tuscany regional level. In addition, they have participated in patient safety walkarounds in hospitals and in developing eight cartoons intended to promote the education of citizens for the prevention of the most diffused risks (such as prevention of infections, prevention of falls and handovers).

Feedback on the satisfaction on tutors, topics discussed and knowledge gained was regularly requested from participants through questionnaires distributed before and after the programme. In general, positive feedback was received; participants appreciated the interactive methods of work, the clarity of the language, and the effort to make difficult problems easy to understand. An ad hoc questionnaire was provided to the participants regarding the methodology of clinical research, always showing an improvement in the self-evaluated knowledge before and after the course. Feedback of the results of the evaluation was also shared with each participant. Most of participants reported their experience to other members of the organization. In particular, in the case of the Regione Toscana training, the possibility of immediately transferring what was learned in the course in all the activities in collaboration with the health institutions, policy makers, and health professionals—such as working groups on patient safety best practices, participation to audits, development of tools to improve health literacy—was appreciated.

Some limitations emerged from these experiences. The selection of participants is the first issue, not only because the training course is accessible to a small number of participants (in general no more than 30 participants), but also because the groups comprised of middle-aged and retired participants, with few younger ones. Additionally, there were few individual patient or family member representatives from patient associations. The majority of those representing patient associations were in managerial or leadership positions. Furthermore, it is difficult to choose between small, local, or bigger regional associations. Residential training courses also restricted the participation for geographical reasons.

The PartecipaSalute and ParteciaSalute-Accademia del Cittadino training experiences show that patients and citizens are willing to get actively involved in healthcare and the research debate. There is a real desire to improve their knowledge and skills on health and research issues and allow some general considerations regarding the active engagement of citizens representing associations and advocacy groups.

In conclusion, it is very important to invest in a process of empowerment aimed to have well-trained activists involved vigorously and constructively in the debate, design, and assessment of health and research. Switching from tokenism to active participation is necessary to effectively partner with patients and the general population to design, plan, and co-produce safer more effective healthcare, while also supporting better more patient-centred research [13, 14].

Also, the training courses are feasible and useful, as has recently been discovered also by pharma or other groups that organize courses mainly focused on drugs and drug development, thus directing the participation of the groups more to market needs than to public health.

Furthermore, this training initiative facilitates the networking among associations in part overcoming the difficulties that derive from personalization and division among the associations representing citizens and patients.

Finally, this illustrates the importance of the design and promotion of training courses with institutions, such as the Regione Toscana, in order to be able to implement projects of real collaboration between institutions, healthcare professionals, and consumers' and patients' representatives.

10.5 Recommendations

A systemic approach to health can provide valuable models for wider implementation of patient safety. A multidisciplinary approach includes the involvement of citizens and patients as unique stakeholders in the design, implementation, delivery, and assessment of health services.

Involving patients in healthcare is an opportunity to bring uncommon points of view into policy making and to create shared knowledge between healthcare professionals and patients.

The implementation of patients' and families'/caregivers' perspectives in the patient journey is the golden opportunity to leverage crucial input, such as experiential knowledge, safer care, patient motivation, and trust and social cohesion into the co-production of safety solutions in healthcare. This represents a way to get closer to person-centred care, to create opportunities for patients to meet and share information and knowledge, to develop structures and policies for patient involvement at different levels (with healthcare systems, universities, and policy makers).

However, little has been done to overcome some healthcare systems barriers: the power imbalance between the doctor and patient, language differences, the lack of diffusion of non-technical skills and, last but not least, the lack of evidence about the value of patient involvement.

To be widely implemented, patient engagement in the patient journey requires courageous leadership, organizational efforts, a wider culture of safety of care, the implementation of multi-level structures for the engagement of patients and resources from smarter spending in healthcare.

Education is the landmark to integrate meaningful patient and citizen engagement in healthcare. Training of patients is the fundamental starting point to develop shared knowledge, co-produce projects, and implement an active multi-level participation of patients and families for the improvement of quality and safety of care.

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