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Where are we in shared decision-making in Italy? A brief updated review



Wo steht Italien im Hinblick auf partizipative Entscheidungsfindung? Ein kurzer aktualisierter Review

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ABSTRACT

The aim of this paper is to provide an overview of the current state of the art concerning patient-centred care (PCC), shared decision-making (SDM), and patient involvement in health care in Italy, by updating the previous versions of the review. In the past 5 years some progress has been made towards a higher involvement of patients in their health care and patient-centredness into the national health care system. The updated scoping literature search focused on articles reporting primary data collected in Italy and showed a great increase in the number of publications. Nonetheless, the research efforts are still relatively sporadic compared to other countries especially as for evaluations of interventions and, most notably, they are not driven by a consistent effort to promote SDM and PCC in clinical practice.

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ZUSAMMENFASSUNG

In diesem Beitrag geben wir – in Form einer Aktualisierung früherer Versionen dieses Reviews – einen Überblick über den aktuellen Stand von patientenzentrierter Versorgung („patient-centred care“, PCC), partizipativer Entscheidungsfindung (PEF) und Patientenbeteiligung im italienischen Gesundheitswesen. In den letzten fünf Jahren konnten gewisse Fortschritte bezüglich einer besseren Beteiligung von Patienten an ihrer Gesundheitsversorgung und einer stärkeren Patientenzentrierung im nationalen Gesundheitssystem erzielt werden. Im Fokus der aktualisierten orientierenden Literaturrecherche standen Beiträge, die über in Italien erhobene Primärdaten berichteten, wobei sich eine deutliche Zunahme der Anzahl von Publikationen zum Thema zeigte. Dennoch sind die Forschungsanstrengungen, insbesondere was die Evaluation von Interventionen betrifft, im Vergleich zu anderen Ländern noch verhältnismäßig sporadisch. Vor allem sind sie aber nicht von dem konsequenten Bemühen geprägt, PEF und PCC im klinischen Alltag zu fördern.

Introduction

The situation regarding shared decision-making (SDM) and its implementation in Italy has been described in the past 15 years by three previous versions of this report [1–3]. The aim of this paper is to update the previous versions by providing an overview

of the current state of the art concerning patient-centred care (PCC), SDM and patient involvement in health care in Italy.

Similarly to the previous updates, this paper provides first some background information on the Italian health care system and policy efforts to promote stronger patient involvement, participation and SDM into the national health care system, then it provides examples of current initiatives in Italy regarding PCC, SDM and

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Table 1

Intervention studies included in the updated review.

Authors	Setting	Aims	Methods	Main findings
Barbosa et al. [16]	Training for medical residents	To assess the effectiveness of a brief training program in relational/communication skills for medical residents.	64 medical residents in total; training program was based on interviews with standardized patients and reflective practice; outcome: independent raters' score on 10 communication skills for breaking bad news and the percentage of providing space and empathic responses, assessed at baseline, after three days and after three months, using video-recorded consultations.	The training program was effective in improving 7 of the ten communication skills assessed and in increasing the space for further disclosure of cues and concerns provided by medical residents. These effects were confirmed soon after the training and lasted at least 3 months.
Bottacini et al. [12]	Oncology	To compare the effect of using a pre-prepared list of evidence based questions (Question Prompt Sheet, QPS) versus a patient self-generated list of questions (Question List, QL) on the number and content of questions during an oncology consultation (primary outcome) and on the satisfaction about questions asked, satisfaction with decision, and level of anxiety (secondary outcome).	Multi-centred, randomized controlled trial; 308 women from three outpatient oncology clinics in Northern Italy.	The number of questions asked during the consultation was similar in both groups, and no differences were found on patient decisional satisfaction nor on anxiety. Patients in the QPS group selected a higher number of questions from the list, and were less satisfied than patients in the QL group, but were also less likely to want more information.
Buizza et al. [13]	Oncology, breast cancer	To compare the effect of Question Prompt Sheet, (QPS) versus Question List (QL) (see [12]) on the oncologist-patient relationship.	Multi-centred, randomized controlled trial; 324 patients with a recent diagnosis of early stage breast cancer	Patients were perceived as 'difficult' by the oncologists more frequently in the QPS group (20.6%) than in the QL group (11.8%). Moreover, there was a small inverse relationship between difficulty perceived by oncologists and the satisfaction of patients for their relationship with the oncologists during the consultation.
Fadda et al. [15]	Vaccination	To compare the effects of 2 smartphone-based interventions targeting measles mumps and rubella (MMR) vaccination knowledge and psychological empowerment respectively, on MMR vaccination knowledge, psychological empowerment, risk perception, and preferred decisional role (primary outcomes).	Between-subject factorial randomized controlled trial comparing 4 conditions resulting from the combination of: knowledge intervention (absent/present) by empowerment intervention (absent/present). Design: before and after study. Sample: 201 parents of young children in Italy.	All interventions increased vaccination knowledge relative to the control condition, whereas only both interventions together increased psychological empowerment. The knowledge intervention yielded increased intention to vaccinate and higher confidence in the decision compared with the control group.
Mariani et al. [17]	Training nursing home staff	To analyze the effects of training nursing home staff in the implementation of SDM on agreement of residents' 'life-and-care plans' with the recommendations (primary outcome) and on family caregivers' quality of life and sense of competence, and staff's job satisfaction (secondary outcomes).	Comparing an intervention condition (with staff attending a training program on the use of SDM with residents and family caregivers in the care planning process) versus a control condition (usual care planning). In-depth qualitative and quantitative analyses of the care plans were performed for primary outcomes. Multivariate Permutation Tests were applied to assess the impact on secondary outcomes. Forty-nine residents and family caregivers and 34 professionals were involved.	Overall, many of the care plans developed during the intervention showed a high level of agreement with the care planning recommendations. Involvement of residents and family caregivers in care planning contributed to an improvement of the residents' care plans, for example by increasing the number of clear problem statements, but it did not have an effect on family caregivers and staff outcomes (secondary outcomes).
Mistraletti et al. [14]	Intensive Care	To investigate relatives' understanding of prognosis, treatments, and organ dysfunction, families' satisfaction, and symptoms of anxiety, depression, and post-traumatic stress in before and after implementing a brochure and website designed to meet the needs of relatives of patients in intensive care units (ICU).	Prospective multicenter before-and-after study, using a self-administered questionnaire. Sample: 332 out of 551 relatives who received questionnaires in nine Italian ICUs responded; 144 before and 179 after implementation of the brochure and website.	The brochure was read by 73% of participants whereas only 19% viewed the website. Nonetheless, the intervention was associated with increased correct understanding of the prognosis and the therapeutic procedures and with a lower incidence of post-traumatic stress symptoms. The intervention had no effect on the prevalence of symptoms of anxiety and depression.
Monzani et al. [19]	General public, hypothetical	To compare patient preferences regarding their involvement in shared treatments decisions depending on a hypothetical discussion with a male and a female doctor, using an ad hoc manipulated version of the Control Preference Scale.	Vignette experimental design; 153 participants.	Participants showed a strong preference for a collaborative role in treatment-related decision-making. Multiple and complex interactions between people's hostile sexism, physicians' gender, and people's gender were found on the preferences for the active role, whereas the preferences for the active-collaborative role was independent of people's gender.
Roberto et al. [8]	Oncology, breast cancer screening	To develop and evaluate a web-based dynamic decision aid (DA) for breast cancer screening	Pragmatic randomized trial, in six centers, comparing DA versus standard brochure (SB). Primary outcome: informed choice (measured on knowledge, attitudes, and intentions) after 7–10 days. Secondary	DA increases informed choice, especially knowledge, but it did not affect attitudes and intentions (very positive in both groups) nor participation rate. Women perceived both resources (DA and SB) as in

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Table 1 (continued)

Authors	Setting	Aims	Methods	Main findings
			outcomes: participation rate, satisfaction, decisional conflict, and acceptability of DA. Sample randomized N = 2119, sample completing study N = 1001.	favor of screening, despite the fact that the DA illustrated pros and cons, overdiagnosis–overtreatment and presented different ways to assess the benefit–harm ratio (controversies). Women receiving the DA reported less decisional conflict than the SB group; they felt better supported and advised about their choice and more confident about it. The results suggest some improvement after the training, including a more frequent exploration of the patient agenda. The main perceived barriers to effective communication were the low patients' cultural level and the poor general knowledge of idiopathic pulmonary fibrosis.
Tomassetti et al. [18]	Training for pulmonologists	To explore the pulmonologist's perspective on physician–patient communication.	27 pneumologists attended at least a workshop of a training course on patient-centered communication; pre-post questionnaires and semi-structured interviews.	

patient participation in healthcare, and, finally, a literature search highlights the articles reporting primary data collected in Italy in the past 5 years on patient involvement, PCC and SDM.

Health care system and policy efforts to promote stronger patient involvement, participation and SDM

The Italian national health care system (called *Servizio Sanitario Nazionale* or SNN), established in 1978, is a public system providing universal and equitable access to services, and it is financed through general taxation, with a budget of approximately 124 billions of euros for 2022 (legge di Bilancio 2022; L. n. 234/2021), corresponding to 6.7% of the GDP. It is organized under the Ministry of Health (*Ministero della Salute*) but administered on a regional basis. The general objectives and fundamental principles of the health care system are defined at the national level, including the definition of the so-called essential levels of assistance (*Livelli Essenziali di Assistenza* or LEA), guaranteed to all residents free of charge, but the administration is highly decentralized at the regional and local level: each of the 20 regions is responsible for the regulation, organization, administration, and funding of publicly financed healthcare and, within each region, a series of local health-care authorities (*Azienda Sanitaria Locale*) directly contract services from private and public providers (for more details see [4]).

The centrality of the individual is listed as one of the most important organizational principles of the national health care system [5], and encompasses a series of rights that can be exercised by individual citizens, including the right to be informed about the treatment and to oppose or give consent and the duty of healthcare planning to prioritize the protection of citizens' health, compatibly with available economic resources.

The centrality of the individual and community is also a key element in the National Prevention Plan (*Piano Nazionale della Prevenzione* or PNP) 2020–2025 that includes actions aimed at improving citizens' health literacy, empowering individuals to act for their and the community's health, and improving the engagement with the health system [6]. Although shared decision-making or patient involvement are not explicitly mentioned, the importance of involving citizens in choices concerning their health is stressed in several parts of the document. For instance, it is recommended explicitly not only to collect but also to use and to communicate data deriving from the surveillance of the population risk factors for chronic illnesses and lifestyles to citizens in order to foster the participation in choices for their health and to empower individuals to adopt healthy lifestyles.

Recognizing that patient-centredness is a key theme for the development of health services targeted by the Italian government, a large national participatory survey has examined patient-centred health services through 387 hospital visits conducted in 16 Italian regions by over 1,500 citizens and health professionals during 2017–2018 [7]. The results were deemed overall moderately positive, but with wide variation of implementation within and between hospitals. Hospitals in the south and islands and those with lower volume of activity had lower levels of person-centred care than hospitals in the north and those with higher volume of activity. The checklist developed to ascertain patient-centredness in Italian hospitals was deemed a useful instrument to monitor the quality of acute care. The checklist covers 4 main areas: 1) person-oriented organizational and care processes, 2) physical accessibility and comfort, 3) access to information and transparency, 3) citizen–patient professional relationship. These areas are further divided in 12 sub-areas, each grouping 2 or more of the 29 person-centred criteria, for a total of 243 items (detailed in Table 3 and Appendix in [7]).

Examples of current initiatives regarding SDM and patient participation in healthcare

The Laboratory of Medical Research and Consumer Involvement, an initiative of the Mario Negri Research Institute is probably the most long-lived initiative of patient participation in healthcare in Italy, especially for the project “PartecipaSalute” (participate in healthcare) that was mentioned in all previous versions of this report, aimed at promoting an alliance between patients' groups and professional societies to ultimately foster better health and shared decision-making. Their work in the field continues, for example in the past years they developed and evaluated one of the few decision aids available in Italian, for women invited to perform breast cancer screening [8].

Another interesting initiative promoted by Slow Medicine, is the campaign “Doing more does not mean doing better – Choosing Wisely Italy”. This international campaign that started in the USA, was started in Italy in 2012 with the overall aim to help health care professionals, patients and citizens engage in conversations about tests, treatments and procedures at risk of inappropriateness in Italy, for informed and shared choices (e.g., [9]). In 6 years the campaign has involved over 40 professional societies, creating a series of 44 lists of practices at risk of being inappropriate and issuing 220 recommendations on tests, treatments and procedures, recommendations that are included in the National System of Guidelines (*Sistema Nazionale Linee Guida* - Istituto Superiore di Sanità).

Table 2

Observational studies included in the review applying a qualitative methodology.

Authors	Setting	Aims	Methods	Main findings
Bailo et al. [42]	Oncology	To investigate which factors can foster an empowered management of the cancer condition from the patient's perspective	Three focus groups with 34 cancer patients on care quality, perception of direct control and relationships within the care context, during the care process.	Care quality and relational support in the care context were more valued than the perception of direct control on patient's treatment, suggesting that empowerment encompass different elements and actions other than medical decision-making, including, especially the relational component of the care process.
Battista et al. [43]	Osteoarthritis	To investigate how patients with osteoarthritis experience their disease and care process.	Qualitative study, semi-structured interviews of 11 patients with osteoarthritis in northern Italy.	Seven main themes were found, including experiencing a sense of uncertainty related to the perception of treatment choices as not based on medical evidence and negative feelings related to not being understood and feeling ashamed or hopeless about their condition. First-line nonsurgical treatments were not considered as an option but a way to fill the time while waiting for surgery. The findings suggest specific issues that can be addressed to enhance patient-centered and shared decision-making treatments.
Mariani et al. [44]	Dementia care	To identify barriers and facilitators regarding the implementation of an SDM framework for care planning in two nursing homes, one in Italy and one in the Netherlands.	Focus group interviews with healthcare professionals (10 out of 19 in Italy) trained to apply the SDM framework. Data were analyzed using content analysis.	Six themes and 15 categories were extracted. Team collaboration, communication skills and nursing home policy were found to be facilitators to the implementation process of SDM. Regulations, lack of funding and lack of involvement of family caregivers were found to be the main barriers. Family attitudes towards SDM could be both a facilitator and a barrier.
Meier et al. [20]	Reproductive health	To explore Italian women's reproductive health decision-making experiences through a shared decision-making lens.	Forty-six reproductive-aged women recruited in Florence, semi-structured interviews in English, analysis based on expanded grounded theory.	Three main themes emerged in the interviews. Most women desired involvement in reproductive health decision-making and highly valued listening and understanding. Decisional role preferences varied, with a desire for autonomy that was mainly framed as respect for their preferences. Finally, the options available and women's decisions were affected by sociocultural factors, including the economy and religion.
Renzi et al. [21]	Oncology, prostate cancer	To assess the qualitative experience of prostate cancer patients during treatment in order to provide insights for clinical practice with a particular focus on the design of a web platform to promote cancer patients' empowerment.	10 patients undergoing radiation therapy; Semi-structured interviews covering four main thematic areas (patient-healthcare providers' communication, decision-making, needs, and resources), analyzed with thematic analysis.	The patient-healthcare providers' communication was poor, with half of the patients reporting little to no possibility to share information and questions with healthcare providers. While patients often preferred an active or shared role in decision-making, the role of healthcare providers was usually perceived as directive/informative. The findings highlight the importance of supporting relations with healthcare providers (especially immediately after diagnosis and after surgery) and self-management after surgery and at the beginning of radiation therapy treatment.

While the involvement of patient associations is important both in clinical research as well as in health policy decision-making to foster patient participation in their care, the few studies that assessed it in Italy showed that there is room for improvement in both domains [10–11].

Updated literature review: Primary data collected in Italy in the past 5 years

Building on the three previous reports [1–3], a literature search was performed using the term Italy and one of the following: shared decision-making, patient involvement, patient-centred care, patient-centred communication, patient

participation and empowerment. In addition, articles citing the two previous reports and articles citing the articles identified by the search described were further inspected. The search was performed on articles published since 2017, when the last report was published. Articles in English and in Italian were considered. Articles were included if they reported data collected in Italy. Letters, opinions, theoretical and review articles were not included.

Since the last update several articles have been published on PCC and SDM in Italy. Nonetheless, the term SDM has not gained prominence and is not frequently used, whereas many articles refer to patient involvement, participation, or empowerment. To note that previous searches were restricted to a stricter domain,

Table 3

Observational studies included in the review applying a quantitative methodology.

Authors	Setting	Aims	Methods	Main findings
Barello et al. [23]	Inflammatory bowel disease (IBD)	To explore the role of the patients' psychological readiness to be active player in their IBD management (i.e. patient health engagement) in affecting patient's HRQoL	Cross-sectional study on 1176 IBD patients. Measures: HRQoL (SIBD-Q) and patient engagement (PHE-s®). Regression analysis was used to examine the effects of patient engagement on HRQoL.	About half of the patients resulted engaged in their IBD care pathway, which was associated with reporting higher levels of HRQoL.
Borghi et al. [22]	Assisted reproductive technology (ART)	To explore the association between patient-centered communication, patients' satisfaction, and retention in care in assisted reproductive technology (ART) visits.	A total of 85 ART visits at eight Italian clinics were videotaped and coded using the Roter Interaction Analysis System, which includes a Patient-Centered Index (PCI), a summary "patient-centered communication" ratio. After the visit, patients completed a satisfaction questionnaire (SATQ). The open-ended item of SATQ was analyzed through content analysis. After 3 months, patients were asked about their retention in care.	Patients were highly satisfied and engaged. TPCI scores revealed a more disease-oriented communication during the visit, however no associations were found among the study variables and the style of physician-patient communication was not found to be associated with patient satisfaction and retention in care. The authors suggest that the actual meaning of a communication that is "patient-centered" in the ART context might be wider, including the couples' need for information, as suggested by qualitative findings.
Ceriana et al. [29]	Amyotrophic lateral sclerosis (ALS)	To explore the extent of shared decision-making process in ALS patients about the issue of tracheostomy, that should be discussed before the onset of terminal respiratory failure, by analysing the episodes of acute respiratory failure preceding tracheostomy.	Based on the charts of a group of ALS patients after tracheostomy and interviews focusing on the existence of anticipated directives, tracheostomies were classified as planned or unplanned according to the presence of a decision plan.	Of the 16% of patients cared for in three years who were tracheotomised, only in 38% of cases the tracheostomy was planned, indicating that patients made a voluntary decision for tracheostomy before the procedure was conducted. It is recommended that guidelines are developed for the timing and content of the shared decision-making process.
Fersini et al. [28]	Obstetrics, mode of delivery	To assess the extent to which pregnant women are involved in SDM about the mode of delivery, with the hypothesis that SDM may help to reduce the rate of Cesarean Delivery (CD).	Fifty-eight outpatient obstetric consultations were rated applying the Italian version of the OPTION12 scale.	Participants showed a very low level of patient involvement in deciding between a CD and a Vaginal Delivery (VD). Women obstetricians resulted in higher scores in patient involvement.
Franchina et al. [10]	Patient associations	To obtain an overview of the real involvement of Italian patient associations in clinical research.	Online questionnaire including 16 questions on the active involvement of patient associations in clinical research, promoted by the Italian Association of Medical Oncology. 46 out of 90 patients associations participated.	The involvement in clinical research working groups, in the organization and implementation of specific activities and training initiatives is very limited and is often limited to drafting of the protocol, patient recruitment and the outline of the informed consent. The participation in projects on patient involvement in clinical research in collaboration with other associations is even more limited.
Graffigna et al. [24]	Chronic conditions	To assess the role of psychosocial factors in promoting patient activation. Specifically, to test the mediational role of Patient Health Engagement (PHE-model) in the relationship between positive emotions, the quality of the patient/doctor relationship, patient activation, and medication adherence.	Survey of 352 Italian-speaking adult chronic patients from a research panel. Structural equation modeling. Measures of: patient activation; Patient Health Engagement model; patient adherence; the quality of the patients' emotional feelings; the quality of the patient/doctor relationship.	The results were in line with the hypothesis, with: a) patients' activation significantly associated with reported medication adherence; b) psychosocial factors (e.g. patients' quality of the emotional feelings and the quality of the patient/doctor relationship) were associated with the level of patient activation; c) the mediation effect of the Patient Health Engagement model was confirmed.
Gualano et al. [26]	Hospitalised patients	To investigate the patients' perception of their participation in treatment choices and to identify the possible influences of variables in decision aids and therapeutic choices, with an evaluation of the impact of SDM on the length of hospital stay and the health expenditure in the region Piemonte.	Cross-sectional study; 174 participants; Ad-hoc 26 items structured questionnaire administered by resident doctors and data from Hospital Discharge Registers. The participation in treatment choices was derived using a dichotomous variable.	More than half of the sample reported a SDM approach, which was more likely in females and younger patients. Additional positive predictors of a ADM approach were: receiving "good" or "excellent" information, having their own request fulfilled and their opinions took into account by healthcare professionals, and the perception that healthcare professionals spent a proper amount of time with the patients and used an understandable language. Whereas the patients trust in the information given by the healthcare professional was not a predictor. No significant difference where recorded in length of stay and hospital expenditure.

Table 3 (continued)

Authors	Setting	Aims	Methods	Main findings
Ingravallo et al. [45]	Palliative care	To investigate whether and when palliative sedation was discussed with hospice patients with cancer and/or with their families and factors associated with patient involvement in such discussions.	Retrospective examination of medical records of cancer patients who died in an Italian hospice in 2014–2015 (N = 326); Multiple logistic regression to assess the association between patients' characteristics and palliative sedation discussion with the patient versus only with the family.	Patient involvement in palliative sedation discussions was negatively associated with living with others and positively associated with awareness of prognosis and days of survival after hospice admission. It is auspicious to implement and monitor policies encouraging patient involvement in palliative care decision-making, including palliative sedation.
Marton et al. [46]	General public, hypothetical	To examine Health locus of control (HLOC)'s relations with people's control preferences about medical decision-making.	153 participants; self-administered version of the Control Preference Scale and the Multidimensional Health Locus of Control Scale – form C.	The collaborative role was the preferred one, whereas the least preferred one was the passive role. Lower scores in external HLOC were associated with a greater preference for an active and a collaborative role.
Marzorati et al. [47]	Oncology	To assess the level of knowledge and awareness about cancer disease and treatment, and patient participation and assistance and compare it between caregivers and patients.	Descriptive, cross-sectional study on a total of 510 participants who directly (patient) or indirectly (caregiver) faced a cancer diagnosis, from five countries (Italy, United Kingdom, Spain, France and Germany). Participants from Italy were 103.	Patients and caregivers highly valued participation in the care process and equally found it important. Some other differences were found between caregivers and patients' perspectives, suggesting possible critical points that may lead to miscommunications and misperceptions.
Minacapelli et al. [48]	Multiple sclerosis	To prospectively assess risk attitudes and personality traits of people with multiple sclerosis (MS) choosing a disease-modifying therapy (DMT).	420 patients with MS from 3 centers; Ad hoc questionnaire including standard-gamble questions, to evaluate MS- and DMT-related risks through two hypothetical drug scenarios.	Both socio-demographic (i.e., being male and of high education) and personality factors (higher impulsivity/sensation-seeking propensity) were related to risk attitude. These findings could affect the shared decision-making process in selecting the best treatment option for patients with MS.
Palumbo et al. [49]	General patients	To investigate the effects of health literacy on individual self-efficacy perceptions, awareness, and health services use.	591 Italian patients; Measures: Newest Vital Sign (NVS) screening tool for health literacy; self-reporting survey for self-efficacy perceptions, awareness and health services use.	Limited health literacy was found to be prevailing and low health literacy skills were associated with poor self-efficacy perceptions, low awareness of health-related issues, low patient involvement and higher risks of inappropriate access to care. The findings suggest that inadequate health literacy is a barrier to health services' co-production and needs to be addressed by health policies aimed at promoting patient involvement.
Ravaldi et al. [27]	Perinatal loss	To investigate to what extent women who faced stillbirth in Italy felt involved in making important choices (i.e. type of birth, encounter with baby, post-mortem examination etc.).	134 women recruited through a patient association completed an online survey	Most mothers who saw the baby were satisfied with their choice (96% vs 11% not-seeing, $p < 0.01$). Having held the baby also led to increased satisfaction with the choice (81.2% vs 14% not-holding, $p < 0.01$). Negative feelings (doubt/regret) were higher among those who were offered to hold the baby after some time compared to those who were offered it immediately after birth. Results of the Control Preference Scale showed that 11.2% of women wanted to 'have the last word' (fully active), 21.2% wanted to leave the choice to doctors (fully passive) and 30.6% preferred a collaborative decision-making process (SDM).
Rosati et al. [25]	Pediatrics	To explore parents' knowledge and views of clinical shared-decision-making (SDM) for their children.	Cross-sectional survey on 458 parents in a single institution. Measures: Ad-hoc questionnaire exploring their general views on SDM, including what doctor-patient relationship predominates today, and what approach reassures them most.	Nearly all parent appreciated SDM, and more than a half felt reassured by it. About half preferred SDM for choosing children's treatment, and over a quarter considered SDM the predominant relationship today. The preference for SDM was stronger for native Italian-speaking than foreign parents and for highly-educated parents.
Russo et al. [50]	Chronic diseases	To analyze the effects of patient empowerment on patients' value co-creation behaviors.	Survey on 250 patients with chronic diseases in the waiting rooms of the local health units of the Lazio region. Analyzed with structural equation modeling.	Findings confirmed that patient empowerment enhanced value co-creation behaviors, supporting the importance of empowering patients in their transformation from passive to active stakeholders, working with providers for the most optimal health outcomes.

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Table 3 (continued)

Authors	Setting	Aims	Methods	Main findings
Solari et al. [51]	Multiple sclerosis, secondary progressive multiple sclerosis	To assess: (a) the characteristics associated with patient awareness of secondary progressive multiple sclerosis conversion; (b) the experience of conversion; (c) importance and prioritization of the 33 needs previously identified (including active patient care involvement).	Online survey, 141 out of 215 participants were from Italy.	Among the pre-specified, “active patient care involvement” resulted in one of the two needs that were prioritized in both countries, and among the other two that differed across countries “an individualized health care plan” and “information on social rights and policies” were prioritized in Italy.
Sommaruga et al. [30]	Healthcare professionals	To investigate whether healthcare professionals’ emotional intelligence (EI) is associated with self-perceived provision of patient-centered care (PCC), taking into account the potential mediating effect of general self-efficacy (GSE)	Sample: 318 healthcare professionals from four hospitals. Measures: Provider-Patient Relationship Questionnaire, Emotional Intelligence Scale, and General Self-Efficacy scale. Analysis: structural equation model.	EI had direct effects on the self-perceived provision of PCC dimensions. GSE partially mediated only the relationship between EI and involving the patient in care. Healthcare professionals in rehabilitation units showed higher self-perceived provision of PCC than those in acute care or ambulatory services.
Truccolo et al. [52]	Oncology	To investigate the interest of cancer patients and caregivers in being involved in patient education and empowerment (PEE) activities.	A total of 875 (29%) users responded to the 3000 distributed questionnaires	Half of participants indicated that they would like to be involved in the organization of PEE activities, particularly caregivers and users above 55 years of age. The preferred educational activities were “classes on cancer-related topics with healthcare professionals” and “cancer information service” on a face-to-face modality.
Turner et al. [53]	Epilepsy	To investigate the level of empowerment, decisional skills, and the perceived relationship with the clinician, of epileptic women in childbirth age, especially women who take valproic acid (VPA), for its specific balance of risks and benefits.	Sample: 60 women with epilepsy. Measures: level of empowerment (Psychological Empowerment Instrument), decisional skills (General Decision Making Style – GDMS scale), and judgment about how they feel to be involved by their clinician in medical decision-making (Observing Patient Involvement –OPTION scale).	The sample presented scores in line with norming scores for their level of empowerment and the frequency distribution of decision styles was equally allocated in all the five components. Moreover, participants felt adequately involved in treatment decisions, and in the management of therapeutic options. For clinicians it would be useful to have specific tools to know if the patient has really understood the risks and benefits of antiepileptic drugs, particularly VPA, and all treatment alternatives.
Vercellini et al. [54]	Colorectal endometriosis	To examine the degree of patient satisfaction in women with symptomatic colorectal endometriosis who choose medical or surgical treatment after a shared decision-making (SDM) process	Chort study on 87 women with an indication to surgery for colorectal endometriosis. A standardised SDM process was adopted, allowing women to choose their preferred treatment. Measures: Patient satisfaction, Variations in bowel and pain symptoms, Constipation (Knowles–Eccersley–Scott Symptom Questionnaire), health-related quality of life (Short Form-12 questionnaire), psychological status (Hospital Anxiety and Depression scale) and sexual functioning (Female Sexual Function Index).	A total of 50 patients chose treatment with an oral contraceptive pill (n = 12) or a progestin (n = 38), whereas 37 women confirmed their previous indication to surgery. Satisfaction with choice was high in both groups and similar at various follow ups. When adequately informed and empowered through a SDM process, most patients with non-occlusive colorectal endometriosis who had already received a surgical indication, preferred medical therapy. The possibility of choosing the preferred treatment may allow maximisation of the potential effect of the interventions.

excluding terms such as patient-centeredness and patient engagement yielding to the exclusion of articles that might nonetheless be of interest for the community of researchers in SDM.

The 40 articles included in this update covered a variety of topics, including but not limited to oncology, multiple sclerosis, reproductive health, stillbirth, dementia, and vaccination. Most studies reported on observational designs with quantitative data (n = 20), qualitative data (n = 5) or described the development and validation of a scale (n = 4) or a usability evaluation (n = 2), only a minority were intervention studies (n = 9).

Intervention studies

The interventions evaluated concerned a variety of settings and used a variety of interventions (Table 1). Two related studies examined the effect of using a pre-prepared list of evidence-based

questions versus a patient self-generated list of questions in the oncology context using a randomised controlled design [12–13]. While both groups asked a similar number of questions during the consultation, patient decisional satisfaction and anxiety were similar [12]. Moreover, oncologists considered patients to be ‘difficult’ more frequently when using a pre-prepared list of evidence based questions than when using a patient self-generated list of questions, and the difficulty perceived by oncologists was inversely related to patients’ satisfaction for their relationship with the oncologists during the consultation [13]. The other intervention study in oncology using a randomised design assessed the effectiveness of an online dynamic decision aid for breast cancer screening against that of a standard brochure [8]. The decision aid had a positive effect, increasing informed choice, especially knowledge, reducing decisional conflict and increasing the feeling of being supported in the choice. However, attitudes and intentions

Table 4

Other observational studies included in the review: scale development and usability evaluation.

Authors	Setting	Aims	Methods	Main findings
Casu et al. [31]	Patients (Inpatients and outpatients in hospitals)	To adapt and psychometrically test a questionnaire to assess and investigate how patients evaluate the provision of patient-centered care (PCC) by healthcare professionals. A tool previously developed for self-assessment of professionals' provision of PCC was adapted into a patient-rated form, named Patient-Professional Interaction Questionnaire (PPIQ).	A sample of 1139 patients from six hospitals completed the 16-item PPIQ and the questionnaire structure, reliability, susceptibility to social desirability, and associations with other variables were tested.	The PPIQ confirmed the original four-factor structure (effective communication, interest in the patient's agenda, empathy, and patient involvement in care) and showed acceptable reliability and measurement invariance across both in-/out-patients and first/non-first encounter with the evaluated professional. Associations with patients' social desirability were negligible and effective communication was rated the highest among the PPIQ dimensions. PPIQ scores varied according to patients' educational level and type of professional evaluated, while associations between first/non-first encounter and PPIQ scores varied according to in-/out-patient.
Esposito et al. [32]	Oncology	To develop and evaluate the psychometric properties of an Italian version of the Decisional Conflict Scale (DCS-ITA), including its factorial structure and its accuracy in discriminating the level of uncertainty.	246 cancer patients deciding about the insertion of a Central Vascular Access Device (CVAD) for intravenous (IV) chemotherapy administration; exploratory factorial analysis and assessments of internal reliability and criterion validity.	The DCS-ITA was confirmed to be a psychometrically sound instrument, with good internal consistency, acceptable construct validity, and good criterion validity, i.e., discriminating between patients who are and those who are not experiencing a decisional conflict.
Fadda et al. [33]	Vaccination	To develop and evaluate the psychometric properties of an instrument to measure parents' psychological empowerment in their children's vaccination decision and propose a context-specific definition of this construct.	Scale of 9 items developed based on previous qualitative data, experts opinion and pilot testing (N = 113). Convergent and discriminant validity were assessed (using the General Self-Efficacy Scale, a Psychological Empowerment Scale, and the Control Preference Scale) in a sample of 245 parents attending vaccines clinics in Milan.	Four items were retained in the Vaccination Psychological Empowerment Scale (VPES) scale, with a two factor structure: one on the perceived influence of one's personal and family experience with vaccination, the other on the desire not to engage with other parents in discussions about their opinions and experiences with vaccination. Both factors were associated with knowledge and intention to vaccinate children and with the measure of empowerment, but no association was found with self-efficacy and the preferred role in decision-making.
Souliotis et al. [11]	Patient organizations	Twofold: 1) To further validate the Health Democracy Index that measures patient organization participation in health policy decision-making; and 2) to provide a snapshot of the degree and impact of cancer patient organization (CPO) participation in Italy and France.	A convenient sample of 188 members of CPOs participated in the study (95 respondents from 10 CPOs in Italy and 93 from 12 CPOs in France). Online a self-reported questionnaire, including the 9-item index and questions enquiring about the type and impact of participation in various facets of health policy decisionmaking.	The index was confirmed to be unidimensional and having good internal consistency. The degree and impact of CPO participation in health policy decision-making were found to be low in both countries; however in Italy they were comparatively lower than in France. It is auspicated that efforts should be made on upgrading CPOs' role in health policy decision-making.
Kondylakis et al. [34]	Oncology, breast and prostate cancer	To present and evaluate a novel methodology employed in the iManageCancer project for cancer patient empowerment in which personal health systems, serious games, psycho-emotional monitoring and other novel decision-support tools are combined into an integrated patient empowerment platform.	Evaluation with 135 adult cancer patients (88 breast cancer, 47 prostate cancer) and 23 families with children with cancer.	The evaluation showed mixed evidences on the improvement of patient empowerment, while ability to cope with cancer, including improvement in mood and resilience to cancer, increased for the participants of the adults' pilot.
Salvi et al. [35]	Different conditions	To provide decision support to the clinicians for the selection of the elicitation method to quantifying the patient's preferences and to bridge the gap between utility coefficient (UC) elicitation and the exploitation of those UCs in shared decision-making.	The elicitation tool was evaluated on 51 volunteers (with three types of medical conditions), who expressed UCs for four purposely selected health states.	The insights on the collected UCs validated the rules included in the decision support system. The usability of the tool was assessed through the System Usability Scale, obtaining positive results.

were equally positive in both groups and the two resources were perceived as equally in favour of screening. Another study, not-randomised, assessed the effects of using a brochure and a website in the context of intensive care, yielding to some improvements in relatives' understanding and stress [14]. The last randomised study was in a different domain, namely immunization, and it assessed the effectiveness of three

smartphone-based interventions (knowledge intervention only; empowerment intervention only; knowledge and empowerment intervention) compared to a control condition on vaccination knowledge and intention [33]. Three of the remaining intervention studies assessed the effect of training healthcare staff (medical residents in [16]; nursing home staff in [17]; pneumologists in [18]), yielding to generally positive results. Finally, a vignette study

examined the effect of the gender of participants and physicians in the role preference in SDM, finding a complex interaction but also showing that the preferences for the active-collaborative role was independent of participants' gender [19].

Observational studies

The five observational studies that used a qualitative methodology (Table 2) were quite diverse but had also similarities. For example, most women desired involvement in reproductive health decision-making and highly valued listening and understanding [20]; also in the context of prostate cancer patients would prefer an active or shared role in the decision-making, although their healthcare professionals are perceived as directive/informative [21].

A variety of studies used an observational design and a quantitative methodology (Table 3). Some studies found positive effects of patients' involvement and engagement. For example, patients using assisted reproductive technology were highly satisfied and engaged [22] and being engaged in their care pathway was found to be a positive predictor of health related quality of life in an ample sample of patients with inflammatory bowel disease [23]. Patients' engagement was also found to mediate the relationship between psychosocial factors, patients' activation and medication adherence in chronic patients [24]. Some studies reported a medium- or high-level of (desired) shared decision-making or patient-centeredness, for example parents strongly favour a shared approach in paediatrics [25], more than half of hospitalized patients reported a SDM approach [26], and about one third of women experiencing perinatal loss preferred a shared approach [27]. On the contrary, in other contexts patient participation in decision-making was unsatisfactory. For example, obstetric patients showed a very low level of patient involvement in deciding between a caesarean delivery and a vaginal delivery, although women obstetricians resulted in higher scores in patient involvement [28]. Only a minority of patients with amyotrophic lateral sclerosis discussed and made a voluntary decision for tracheostomy before the procedure was conducted, calling for guidelines for the timing and content of the shared decision-making process in this context [29]. Only one study focused primarily on health care professionals, showing that their emotional intelligence is associated with self-perceived provision of patient-centred care, and that the relationship is partially mediated by the general self-efficacy [30].

Four studies reported on the development or adaptation and evaluation of a scale: the Patient-Professional Interaction Questionnaire [31], the Italian version of the Decisional Conflict Scale [32], the Vaccination Psychological Empowerment Scale [15], and the Health Democracy Index, measuring the participation of patient organizations in health policy decision-making [11], (Table 4). Finally, two studies reported on the usability evaluation of an integrated patient empowerment platform for oncology patients, part of the *iManageCancer* project [34] and of a decision support tool for the clinicians to select the elicitation method to quantifying patient's preferences [35].

Discussion and conclusion

In the past 5 years the situation has not greatly changed, although some progress has been made towards a higher involvement of patients in their health and the number of publications on the topic has greatly increased. Indeed, only 13 articles reporting data collected in Italy were identified in 2007 considering the previous 20 years [3], 11 additional articles with primary data were found in 2011 [2] and 12 original articles

were reported in 2017 [1]. In the present review 40 publications reporting primary data collected in Italy published in the past 5 years were identified.

The research conducted in Italy in the past 5 years is therefore growing, covering a wide variety of medical contexts, but it is still relatively sporadic compared to other countries and, most notably, it is not driven by a consistent effort to promote SDM and PCC in clinical practice.

It should be acknowledged that some progress has been made towards a higher involvement and participation of patients in their health, but the terms PCC and especially SDM are seldom used in policy documents and recommendations.

Some progress has been made also in available measurements, for example by validating the Decisional Conflict Scale in Italian [32] and by validating a measure of patient organization participation in health policy decision-making (Health Democracy Index [11]). Additionally, a patient-reported measure of SDM has been recently validated [36]. These measures add to those already available in Italian, that are the Control Preference Scale, validated in the context of multiple sclerosis [37] and available also as an online version [38], the OPTION scale, validated in Italian [39–40], the Patient Involvement in Care Scale translated and culturally adapted [41] and the Shared Decision-making-Questionnaire (SDM-Q-9, <http://www.sdmq9.org>), available in Italian, although not formally validated.

Finally, to have a broader picture it would be helpful to ascertain the current level of education in medical curricula addressing SDM and patient centeredness but no such information is available. Among the articles identified in this review, only three concerned an intervention aimed at improving health professionals skills [16–18]. The results seem promising, although limited. For example, a brief training program was offered to medical residents using interviews with standardized patients and reflective practice to improve relational/communication skills for breaking bad news and the training proved effective for at least 3 months [16]. Nonetheless, it would be essential to foster PCC and SDM in medical curricula and in continuing education in order to form future healthcare professionals. The promotion of PCC and SDM through guidelines and policy recommendations could facilitate their implementation. It would be also useful to monitor the status of accomplishments overtime, for instance by using the checklist developed by Cardinali and colleagues to assess patient-centred care [7] and repeating the survey to ascertain areas and sub-areas that need improvements, both at the national and at the local level, reducing the differences between hospitals and regions.

Conflict of Interest

The author declare that there is no conflict of interest.

CRediT author statement

TG: Conceptualization; Investigation; Writing original draft.

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