Chapter 5 Shared Decision Making



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Abstract This chapter is divided into three sections. The first section introduces the concept and models of shared decision-making as a framework of personcentered care. The second section focuses on multicriteria decision-making techniques in healthcare settings and literature review about multicriteria decision making analysis methods used in healthcare is presented. The third section introduces the ethical and practical considerations about shared decision-making in person-centered care. In this section, the patient narratives are included, as well as the barriers to implementation.

Keywords Shared decision-making · Person-centered care · Healthcare · Multicriteria decision-making

5.1 Introduction

Decision making (DM) is one of the most important activities in the healthcare system and medical practice. Because health outcomes are probabilistic, most decisions are made under conditions of uncertainty [30].

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Person-centred care is a valuable approach to improve health care outcomes, so involvement of the patient/person in health care decisions could be beneficial for all interested parties.

5.2 Shared Decision Making Models as a Framework of Person-Centered Care

Shared decision-making (SDM) can be analysed as a model of collaborative practice in which decision-making is delegated, shared and intertwined in all directions of the traditional value chain. At the primary level of health care, SDM models have a particularly difficult and demanding path from development to implementation, bearing in mind that they imply breaking the traditional monopolistic hierarchy of decision-making in which doctors' opinion was primary and almost predominant in decision making. Shared decision-making models, however, do not aim to degrade the role of any participant in the decision-making chain, or to strengthen another participant, but to increase the involvement of all participants in the decision-making chain, at all levels of decision-making.

Laws and professional guides have adopted SDM vocabulary: the World Health Organization considers "autonomy while respecting the involvement of individuals (patients) in their health choices" [31]. The guides from the health ministries of Canada, the United States, the United Kingdom and Australia describe and recommend SDM as part of health studies and vocational training programs, and an integral part of good health practice. For example, in the UK, the General Medical Council emphasizes: In whatever context health care decisions are made, it is necessary to work with patients in partnership to ensure a high level of health care while improving health outcomes. Finally, it is necessary to:

- Listen to patients and respect their views on their own health
- Talk to patients about their diagnosis, prognosis, therapy, and health care
- Share with patients the necessary information to be able to make decisions
- Maximize patients' opportunities as well as their ability to make decisions for themselves
- Respect patient decisions.

In 2008, the General Medical Council also said that non-compliance and absence of patient adherence could put the entire health system in danger.

As the biggest problem for the successful implementation of SDM, the American Health Association finds in the professional education of medical doctors, which teaches them that they must always have the right answer, as well as that they must always have the final decision, and operate separately from other decision-makers in the health system. Although significant progress has been made in interprofessional education and communication to this end, SDM is still underdeveloped despite several simulations and virtual patients as an approach to studying SDM [22].

Shared decision-making (SDM) has often been described in the context of various kinds of physician-patient relationships. One seminal paper on this topic [21] describes four types of models and their relationship to decision making regarding patient care:

- (1) In the paternalistic model of care, the physician is the patient's guardian [7, 59]. He/she determines the best course of action for a particular patient and presents information that will encourage the patient to consent. In extreme versions of this model, the physician takes an authoritative role and makes a decision for the patient, with the patient informed of the next steps.
- (2) In the informative model of care, the physician is a technical expert who informs and implements the patient's wishes [7, 59]. He/she communicates facts to the patient about the disease and various treatment options. All information related to the advantages and disadvantages of these options are presented to the patient who makes a decision, in accordance with his/her values, as to how to proceed.
- (3) In the interpretative model of care, the physician is a counsellor [40, 50]. In addition to providing information, he/she assists the patient in clarifying goals and values, and helps the patient to understand which treatment options might align with these aims. Through this joint process, the patient learns more about himself/herself and makes a decision. In extreme versions of this model, the physician looks at the patient's life as a narrative whole, and then identifies the patient's values and priorities.
- (4) In the deliberative model of care, the physician is a teacher or friend who uses dialog to engage with the patient on the best treatment option [23]. He/she helps the patient with moral self-development and, in this way, empowered to consider all health-related values and their worthiness as related to implications for treatment.

Each of these models involve aspects of patient autonomy and purport a different degree of shared decision-making. Certain models may be more appropriate in specific clinical situations than others, or for those with particular patient characteristics. However, [21] argue that the deliberative model is the ideal physician-patient relationship when implemented effectively. This deliberative model, in fact, espouses the concepts of autonomy, empowerment, and SDM that constitute the Gothenburg model of person-centred care, which focuses on co-creation of care through partnership [17].

Although the active ingredients of the Gothenburg Person Centered Care (PCC) model have not been studied separately, a large body of scientific evidence across various settings in Sweden demonstrate the relationship between PCC and care outcomes [6]. Deliberative SDM specifically, then, maybe contributing to these positive results.

As alluded to previously, SDM has historically been a heterogeneous concept. Therefore, it is not surprising that conceptual models linking SDM to health outcomes are lacking in the literature. Various models do exist to explain the potential relationship between SDM, as a form of physician-patient communication, and health

outcomes. The model by Street and colleagues [56] is of particular relevance. Using a broad definition of health outcomes that includes both physical health and emotional well-being, both direct and indirect pathways linking physician-patient communication to health outcomes is hypothesized. Applying this model to deliberative SDM in the context of PCC, SDM might enhance care outcomes via one or two indirect paths:

- (1) via proximal outcomes of the care interaction on the patient, such as increased satisfaction with the encounter, understanding of condition and options, trust in the care provider, feeling recognized/validated/heard/known, feeling involved in care decisions, motivation to take responsibility for own care, and/or
- (2) via proximal outcomes leading to intermediate outcomes affecting the patient, potentially including improved access to needed care, quality medical decisions affecting care, commitment to treatment, trust in the system in which care is received, social support, and selfcare skills.

Shay et al. [55] adapted this model to incorporate elements from the Transformation Model of Communication and Health Outcome by Kreps and colleagues [32]. This model describes how health communication, including SDM, might impact various aspects of the patient. Physician-patient communication might influence cognitive-affective components (e.g., trust, satisfaction), behavioral components (e.g., adherence, adoption of health behaviors), and/or physiological components (broadened to include self-rated health, quality of life, and clinical indicators such as blood pressure). This model was found to be an especially useful heuristic to synthesize the existing literature on SDM and health outcomes.

The number of scientific publications examining SDM's use, effectiveness, and relationship with health/care outcomes has increased exponentially in the past decade. However, the first published systematic review on patient outcomes and SDM occurred in 2015. Shay et al. [55] review articles with shared decision making in the title published in 2012 or prior. To be included in the review, all articles had to collected data on:

- (1) at least one perspective of SDM: from the patient self-report, clinician self-report of using SDM with patients, or observer-ratings of the use of SDM (e.g., via structured qualitative coding of audio-recorded encounters
- (2) at least one patient outcome: affective-cognitive, behavioral, or health.

Forty-one articles from 39 unique studies across various clinical contexts were identified for synthesis. The large majority of studies measured SDM via patient self-report (n = 33; 85%), while 15% (n = 6) used observer rating, and only 2 (8%) used clinician self-report.

Regarding patient outcomes, 97 different assessments were categorized with just over half as affective-cognitive (51%; n=50 with half of these examining patient satisfaction), 28% were behavioral (n=27), and slightly more than a fifth were health (21%; n=20) outcomes.

Of the 97 relationships between SDM and an individual patient outcome, less than half (n = 42; 43%) were statistically significant. They created a 3×3 table and examined the number of significant relationship by SDM measurement perspective and type of outcome. Significant associations were most common (52%) when the patient reported SDM occurred, while only 21% of associations were significant when SDM was observer-rated and 0% when clinician-reported. Significant associations were also most common (54%) when affective-cognitive outcomes were examined, while only 37% of associations were significant when outcomes were behavioral and 25% when they were healthy. It is important to note that negative associations between SDM and patient outcomes were also noted in three articles. In summary, when the patient feels involved in SDM, they are also more likely to report more trust in their provider and satisfaction with care.

The former systematic review suggests that much more nuanced research into the potential relationships between SDM and patient/care outcomes is required to enhance understanding into potential mechanisms of action. In particular, additional emphasis on non-self-reported outcomes is warranted. In this respect, it is important to note that over 20 studies in Sweden based on 15 controlled clinical trials in 11 different disease/clinical areas with 2,610 people have been conducted examining the impact of the Gothenburg model of PCC on patient outcomes [6]. These findings suggest that PCC, which includes SDM, can impact patient outcomes in ways that go beyond individual perception. Such outcomes include lower gestational weight gain [25], shorter lengths of hospital stay [18, 46, 47] and cost savings [26]. While it is difficult to thease apart the active components of the Gothenburg PCC intervention, deliberative SDM can be considered to be closely associated with core PCC routines of creating, working, and maintaining a physician-patient/person partnership.

SDM concept could be consider from 3 perspectives: on the individual (micro) level, on the organisational (meso) level, as well on the policy-making (macro) level.

Individual (Micro) Level

The patient's benefit of SDM is that patients develop preferences based on their comprehension of accessible information. Patient/person has more realistic expectations, less "decisional conflict" as currently measured, and greater satisfaction. Shared decision-making can improve adherence and increase trust [10].

Individual-level effects on healthcare professional (HCP) should also be considered; the experience of supporting patients in arriving at informed decisions may be intrinsically rewarding. HCP may also find the effort involved emotionally and cognitively taxing, adding to their workload burden. These consequences for clinicians should be evaluated and understood as they should be expected to influence the uptake of shared decision-making [20].

Organizational (Meso) Level

The impact of shared decision-making as a communicative process has the enormous benefit on patients. But share decision making considers communication among the HCPs, as well as pharmacists, nurses. It can facilitate interprofessional barriers. Experts in organizational psychology consider five types of potential outcomes: (a)

tangible outcomes products of teaming, e.g., costs or rates; (b) attitudes or emergent states, e.g., trust, psychological safety; (c) cogni-tive states, e.g., shared mental models; (d) team behaviours, e.g., turnover or absenteeism; and (e) norms, e.g., expected behaviours [20].

Policy-Making (Macro) Level

Shared decision-making has been welcomed by policy-makers world wide—it resonates and supports the ethical imperative of respect for patient autonomy and engagement [20].

One of the most cited SDM models that reflects all levels of the healthcare system is the **Interprofessional shared decision-making model** (IP-SDM) proposed by Légaré et al. [33].

In order to talk about an interprofessional approach to SDM, the IP-SDM model must include at least two health professionals of different professional orientations who either simultaneously or in various phases cooperate with each other in the SDM process with the patient. Communication on the individual (micro) level considers 6 steps.

Step 1: First step presents the patient with the health problem and requires a decision. A counterweight is a situation in which there is a decision point with more than one option and for which it is necessary to "weigh" each option well—the advantages and the disadvantages for each.

Step 2: This step involves exchanging information regarding options relevant to the patient's health condition. Healthcare professionals and patients share information about the potential benefits and potential side effects of each of the options, using educational materials, patient decision aids, and other evidence-based sources. Patient decision aids are tools that help people involved in decision-making processes, providing all the details, ie. information on all the benefits and dangers that this decision brings with it. Likewise, the participants in the IP-SDM process, discuss about the options available.

Step 3: Requires valuation by SDM process participants. Although patient values are the most important for making the right decisions, this model recognizes all the values that all SDM participants add to the system. Also, future research should consider the impact of numerous value sets on the IP-SDM process.

Step 4: Emphasizes the need to consider the feasibility of each of the options during the SDM process. Given the different business conditions in different countries, and thus in health care systems, SDM options will also differ. For this reason, local expertise is definitely not trivial for the functioning of this conceptual IP-SDM model.

Step 5: In this step, the essential decision is made. With the help of various experts, the patient decides on the preferred option. Healthcare professionals may also have their preferred option to share with the patient in the form of their recommendation. Ideally, both the patient and healthcare professionals would agree on the final option. After that, health professionals would organize a whole set of measures and procedures

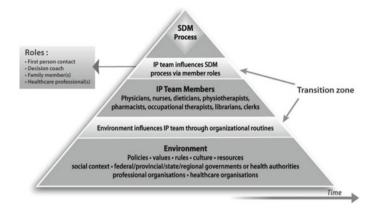


Fig. 5.1 IP-SDM model—healthcare system (meso and macro) levels representing the global influences in which the individual level is embedded (Légaré et al. 2010)

by which the patient can access the desired option. In case of disagreement, the final decision may be postponed.

Step 6: Involves patient support, so that the chosen option has the best impact on positive health outcomes, while achieving higher values (levels) of health service.

IP-SDM influence on the meso and macro levels is shown in Fig. 5.1.

At the top of the pyramid in the Fig. 5.1 represents the individual level of the process, which is explained earlier, trough 6 steps. Other parts of the pyramid depict either elements or persons from the health care system that may affect SDM. The dark shaded part in the middle, represents health professionals who can be involved in the SDM process (meso level). The dark shaded part at the bottom symbolizes the elements of the global environment—resources, government, cultural values, professional organizations and rules (macro level). Finally, the two transition zones represent the way in which elements of the health care system and individuals affect SDM. According to the top, the health care system acts on the processes of SDM through the rules implemented by its participants. For this reason, the team must develop mutual communication that is original, constructive and open, in order to foster mutual respect between SDM members, as well as between the team and the patient. At the lower level of the pyramid, the influence of the global environment on the organization of the team and on its functioning is explained.

The model also highlights the impossibility of functioning of interprofessional SDM outside the influence of factors at all levels of health care. Thus, within health teams (meso level), the interprofessional approach to SDM is influenced by the professional role of each individual member, and each professional role of the member is nurtured or limited by organizational routines or innovations within teams. Teams are also part of a larger organizational and social unit, which unite in a global environment (macro level). Despite the existence of good cooperation within IP-SDM teams, they necessarily require the support of the government, its policies

and the leaders of health system organizations, as well as the sharing of a common goal. If there is no harmonization of common goals at all levels of the graphically represented pyramid, the implementation and successful functioning of the IP-SDM model is immediately disabled. Thus, the common goal is a *condition sine qua non* of the successful functioning of the entire system of IP-SDM models. Without a common understanding between health professionals, regulators, decision-makers, public opinion, and other stakeholders, there are inevitable difficulties in both effective communication and an understanding of the common goal across all levels of competence. Leger et al. revised this original IP-SDM model and validated them in primary care. Revision considered terminology change: instead "patient"—more convenient term "person". The revised model merges the micro, meso and macro levels in an integrated version that can help inform an IP approach to SDM in primary care [34].

The latest systematic review about SDM in health care included 50 articles and each describing a unique SDM model [27]. Twelve models were generic, the others were specific to a healthcare setting. All models consistently share some/same components: *Make the decision, Patient preferences, Tailor information, Deliberate, Create choice awareness,* and *Learn about the patient*. The overall conclusion was that a unified view on what SDM is still lacking.

Critical ingredients of SDM, and their overlap with PCC, could be further explored. Such work could help to advance the field of SDM by contributing new aspects of SDM measurement and potentially enhance understanding of the link between SDM and objectively measured patient outcomes.

5.3 Multicriteria Decision Making Techniques and Shared Decision Making

As stated in the previous part, shared decision making (SDM) describes a collaborative process in which healthcare providers and patients/families make treatment decisions using the best available evidence, while taking into account the patient's values and preferences.

If we take into account person-centred care as one of the most important frameworks to improve patient outcomes, in which the same parties as in SDM are involved, we come to the urge for techniques and methods that can support such a complex decision-making process.

This decision-making process is complex on its own because many parties (patients, healthcare professionals, reimbursement funds, health authorities, policymakers, etc.) with different perspectives and approaches are involved, and it is getting even more complex with the evolution of evidence-based medicine with new "big data" and "real-world evidence (RWE)" approaches in order to gain the best scientific evidence currently available.

If we want to have implementation of SDM in the best way, we need to have access to current evidence comparing expected outcomes of decision alternatives, assessment of decision-related values and preferences, and integration of this information to identify the most suitable course of action. Since decisions in healthcare settings are not unique and significantly different from other areas, methods that are well-known and are in use for many decades can be utilized.

Multi-criteria decision analysis (MCDA) methods fulfil all of the required elements of SDM, and this suggests that MCDA methods could be used effectively to facilitate SDM in practice [42].

Multiple criteria-decision making (MCDM) refers to making decisions in the presence of multiple, usually conflicting criteria, allowing with its methods involvement of different (also often conflicting) stakeholders' perspectives, preferences and values, which are then mutually compared, analysed and unique decision is made which represent the best compromise solution for everyone involved in decision making process.

Benjamin Franklin could be one of the first advocate of MCDA as he was using a paper-based system when making important decisions. He would write down the arguments for and against one decision on different sides of the paper, after that he would strike out those arguments on each side of the paper that had relatively equal importance, and when all arguments were eliminated on one side, he would look on the other side, if there were no arguments left, he would make decision [15].

Multi-criteria analysis (MCDA) is a general term that includes a number of analytical techniques used in the decision-making process in the context of multiple, and often conflicting criteria. These techniques serve to support decision-makers on how to agree on which evaluation criteria are relevant, how important these criteria are, and how this information can be used as an alternative procedure (option). MCDA encompasses a broad set of methodological approaches, derived from operational research but with a rich intellectual foundation in other disciplines [42].

Process of MCDA could be simply described in following way: first, identify interventions to evaluate, then identify criteria against which to evaluate the interventions, then measure the interventions against the criteria and at the end, combine the criteria scores to produce a ranking of each intervention [15].

Often, in literature, many terms can be found that are used interchangeably without universal definitions of them, we suggest when screening literature for MCDM, specially in healthcare, you should include all of the following terms: "multiple objective", "multiple criteria", "multiple attribute", "multi-objective", "multi-criteria", "multi-criteria decision analysis (MCDA)", "multi-attribute decision making (MADM)", "multi-objective decision making (MODM)", "multi-attribute utility theory (MAUT)". We think that distinguish should be made, where differences in practise exists, and that is of high interest that universal definitions of these terms in healthcare settings and consensus about them are made. In this chapter, we will use MCDA, MCDM and MODM as synonyms.

The use of MCDA in health systems is on the rise, a number of published papers in previous years are growing rapidly, and it should be seen as a natural continuation of evidence-based medicine assessment and RWE implementation. The MCDA also

provides a set of techniques for determining which performance elements (criteria) need to be measured, what is their importance, how stakeholder preferences can be expressed, and how performance data and preferences can be combined to assess alternatives [42].

The challenge for users of the MCDA method is that a large number of different MCDA techniques are available, and there are few guidelines available on how to decide which technique to choose from all available. For model building most frequently used methods are: Value measurement models (Multi-attribute Value Theory, Multi-attribute Utility Theory, Analytical Hierarchy Process), Goal Programming, Reference models, Outranking model (ELECTRE method, PROMETHEE method, GAIA method). The four most commonly used MCDA methods are [42]: Direct rating, Keeney-Raiffa MCDA, Analytical hierarchical process and Discrete choice experiment.

All of these methods have its advantages and disadvantages, and carefully method should be chosen from case to case. Many of these techniques are already being used in healthcare decision making process, but on the other hand many of them yet have not been, and further research of implementation of these methods in practise using real world data in SDM should be done.

Marsh et al. illustrated how two MCDA methods—the conjoint analysis and analytic hierarchy process (AHP)—have been used to foster shared decision-making in clinical settings [42].

The importance of MCDA in a healthcare setting is evidenced by the EVIDEM framework which promotes transparent and efficient healthcare decision-making and provides a collaborative framework [24] and also by the fact that ISPOR established a working group for new good practices for MCDA ("Emerging Good Practices Task Force for MCDA") in 2014, and since then two reports have been published which define MCDA in healthcare settings, provide guidelines for conducting it, procedural values of MCDA and basic steps to be followed [43, 57].

Examples of countries where some of the MCDA techniques have been applied to support health decision making are: Canada, Germany, Lombardy in Italy, Hungary, South Africa, Thailand, New Zealand and many others [14]. Recently published article suggests possible use of MCDA in benefit-risk framework, for European Medical Agency (EMA) and Food and Drug Administration (FDA), and mentions EMA's experience in the IMI-PROTECT projects [2].

Many examples of MCDA use in healthcare settings which involves SDM can be found, only some of them (as a representation of its possible diversity applications) which are published in 2020, are given in the Table 5.1.

There is broad spectre of MCDA use in healthcare, especially in SDM process, on different levels: from individual level (micro level)—the best therapy choice for one patient; meso level—prioritization for hospital admission of patients in one city; to macro level—evaluation of new technology (not) to be reimbursed, guidelines development, prioritization of the dossier evaluation at regulatory authorities.

The best way to explore advantages and disadvantages of each technique and to make them more visible and acceptable to decision-makers on macro-level is to fund and promote: development of global guidelines and consensus on defining

Table 5.1 Selected articles of MCDA use in healthcare setting in 2020

Author
De Nardo et al. [12]
Ruggeri et al. [49]
Angelis et al. [3]
Hsu et al. [28]
Campos et al. [8]
Camps et al. [9]
Bakhtiari et al. [5]
Jiang et al. [29]
Lvovschi et al. [39]
Panattoni et al. [48]
Schey et al. [54]
Archer et al. [4]

terms, wording and how to conduct MCDA in healthcare settings; implementation of different MCDA techniques as much as possible; mutual comparison of different MCDA methods on the same topic. The most important is to involve in all these researches not only all interested parties rather all possibly involved and impacted parties in decision making process (eg. patient representatives, regulators, policymakers).

The first book related to this topic and its importance is "Multi-Criteria Decision Analysis to Support Healthcare Decisions" published in 2017 [42], and we strongly recommend it to anyone who wants to step into the amazing world of MCDA.

5.4 Ethical and Practical Consideration About Shared Decision-Making in Person-Centered Care

The focal point of person-centered care (PCC) is treating patients in a broad context, not only through the prism of their illnesses and biomedical tests, but most of all perceiving them as persons with all their capabilities and limitations [17, 38]. PCC means moving from a model where patients are passive targets for medical intervention to a model where more partner-like arrangements are made involving the patients as active partners in their care. Co-creation of care and partnership between patients, their families, and healthcare professionals is an essential element of PCC. The GPCC model of PCC entails three pillars consisting of: (1) initiating a partnership by inviting the patient to narrate about their daily life in relation to their condition, the sick person's description of their illness, symptoms and their impact on their life; (2) the process of shared decision-making, based on the unique narrative of the patient and the generic knowledge of the professional; (3) the process of safeguarding the partnership by documenting the sick person's narrative and a jointly agreed care plan that is regularly reviewed and updated [6]. The above brief description indicates that PCC is a very complex approach in many points overlapping with shared decision-making (SDM).

The Patient Narrative in SDM

Central notions in PCC and SDM is patient narrative. The notion 'patient narrative' suggests a rich base of information about a patient, in addition to biomedical tests and physical examination. The information delivered by patients through the 'narration' promises complexity and multidimensionality of the information, including not only patient's values and preferences but also experiences and wants that have to be included in clinical decision making. PCC and SDM call for a patient narrative to be 'holistic', which means to embrace all aspects of the patient's situation, from biomedical, over psychological to social and existential aspects or problems. Some of them might be sensitive details about personal feelings, social relationships, and embarrassing aspects. The 'holistic' approach, however, may bring many ethical and practical issues that should be considered in order to provide more benefits than harm through using SDM in PCC [45].

Early theorists of SDM, believed that safeguarding a deliberative dialogue between caregivers and patients would by itself protect against paternalism and promote patient autonomy in a way undoubtedly required from the ethical perspective [21]. The practice, however, is far more complex and challenging [11, 52]. It has to be noted that SDM in healthcare is significantly different than in other areas, for example, in commercial business. In a business partnership, partners may be coequal in terms of knowledge and power, and bear the same consequences of the decisions made. In the medical encounter, professionals know medical facts that patients do not, patients, on the other hand, have an experience of illness that is unique and probably never was and will be an experience of professionals, and patients, not

professionals, will bear the consequences of the shared clinical decisions [58]. These create inescapable asymmetries and discrepancy of interests.

PCC and SDM assume professionals' competencies to comprehend such 'holistic' and multi-dimensional problems [41], as well as the capability to identify and record the most relevant details in order other professionals, could use it. The documentation is especially important when the PCC approach is implemented in the whole chain of treatment in the medical organization, and patients suffer from several different illnesses what is common in an older population. In such circumstances documented patient narrative should follow the patient route through different professionals and providers, that the patient does not need to repeat the narrative again and again.

However, it has to be acknowledged that the description of the patient narrative recorded in clinical documentation may be biased. Tonelli and Sullivan [58] suggest that clinician values and subjective judgments may enter into the clinical relationship before the diagnosis and negotiations determining what symptoms and features are the most important to investigate and highlight in the documentation. Any attempt to oblige clinicians to provide unbiased information about patients' narrative is doomed to fail. Depriving professionals of including their values in their clinical work is inconsistent with recognizing also professionals within the clinical encounter in the SDM paradigm [44]. In the PCC approach, SDM is an ongoing process within which the patient narrative can be continuously added, revised, and interpreted. This means that time is needed for the narrators to deliver their stories and the listener to understand and analyse them. Therefore, managers of medical providers have to ensure that professionals have access to adequate resources [36] to manage patients' narrations appropriately [41].

Boundaries Within Which PCC and SDM Brings Benefits to Patients

SDM concept had some barriers for implementation.

Patients generally do not expect SDM in the health care system, nor do they have any objections to its absence. They often feel powerless and submissive when meeting with health care providers. Also, the lack and limited time is the most frequently cited reason by doctors for the impossibility of successful implementation of SDM concept in everyday practice. Although SDM does require more time spent in consultation with patients, studies have not identified any link between improving the level of communication with extending the time spent specifically on communication [33].

Documentation and distribution of the patient narrative may benefit as well as harm patients. Information from patient narrative could be used in decision making in ways that promote and protect patient autonomy, as well as in a paternalistic manner [52]. Wider knowledge about patients may empower professionals to better assist patients in clarifying their own ideas and decisions about their care in the context of their life. However, this knowledge may also provide wider opportunities for manipulating, confusing and interfering with patients' decision making in ways that reduce their autonomy. Interfering with patients' decisions may not be the result of a purposeful paternalist strategy of professionals, but maybe the result of a lack of their skills and knowledge about how to manage the patient narrative and dialogue needed for shared decision making [19]. This may increase the risk of professionals'

mismanagement the SDM so that the patient is harmed rather than benefited. For example, when the knowledge about medical aspects conveyed by professionals to patients would be too technical and difficult to comprehend, patients could become blocked in their decision making.

Wide implementation of PCC and consequently SDM in medical providers may make patients feel pressed to talk more about their personal life, intimate feelings, or difficulties in social relationships than they would otherwise have liked, giving room to retrospective regret and unease and affect trust in professionals [35]. A patient's broad narrative about their personal problems may also emotionally burden professionals, especially when they would be untrained or feel a lack of organizational support. Thus, expanding the practice of SDM in an organization calls for the implementation of monitoring and evaluation to assure that the benefits are not accompanied by harmful effects [45].

The problem is that in practice, during the implementation of PCC and SDM, professionals are rather not trained on how to handle and prioritize knowledge about patients' lives. This issue is also not mentioned in the WE-CARE Roadmap, a framework supporting the implementation of PCC [37]. Similarly, not all patients are prepared to adequately match treatment options to personal preferences and values, taking into account rather long-lasting effects than immediate well-being. Thus, effective implementation of PCC, require to follow the narrow space between patients' sufficient narrative and their capacity of autonomy and between professionals' skills to handle the narrative and their ability to present adequate treatment options in a way understandable to patients.

Professionals may select and document information from the narrative in a way that may promote either paternalist or autonomy strategy. This may not only depend on professionals' attitude but also on professionals' subjective judgment about patients' capability to make autonomous decisions, which is apparently a matter of a continuous range [51]. But to support the subjective judgment of professionals about patients' decision-making competency, theoretical or ethical recommendations have to be established. Although from the above discussion appears that SDM would be most suitable for decision-competent patients, the practice of PCC seems to regard patients with significant cognitive decline, such as patients with dementia (e.g. [13, 16]. In PCC this decision incompetency is resolved by the inclusion of other people, such as adult children of demented elderly people. However, the inclusion of other people in SDM raise questions about whether adult children are more competent to make actually paternalistic decision then professionals? And whether the interests of the family that take care of the cognitively impaired person are in concordance with the interests of the person? There are also other questions related to the benefits of PCC and a person's autonomy. For example, whether relocating decisional authority to decision incompetent patients may foster them to become more competent or improve their compliance or adherence [53]?

There is also another issue, that not all patients wish to talk much about themselves and engage much in decision making [1], thus their inclusion in PCC:

'seems to imply a sort of meta-paternalism: the idea that patients need to engage in PCC/SDM procedures to access further care seems to mean forcing, pressing or manipulating some people to engage in (allegedly) autonomy and/or health-promoting procedures against their wishes (a sort of paternalism that would remain even if the goal of PCC/SDM was assumed to be entirely focused on autonomy promotion). This highlights further the lack of basic ethical clarity regarding what are supposed to be the point and limits of PCC/SDM in autonomy and paternalism terms. It also makes salient the existence of different autonomy ideals that PCC/SDM may be related to.' [45].

One more narrow passage that PCC practitioners must navigate is the shift from compliance to adherence in relation to the paradigm of evidence-based medicine (EBM). While compliance is the following of doctor's instruction who are obliged to prescribe the best possible therapy according to EBM, adherence is a patients' proactive behavior capturing the idea of professionals permitting patients to take part in clinical decision making and to correct professional clinical judgment following patients' preferences, values and wants. Thus, adherence as an ingredient of PCC and SDM strengthens patients' influence of the treatment plan, which at the starting point should be the best option according to EBM. This raises the ethical issue to what extent professionals may accept patients' autonomy in decision-making about treatment plans knowing that patients' demands may compromise clinical outcomes. What about professional responsibility and the Hippocratic Oath? How far the professionals can go in terms of persuasion, incentives, and pressures to influence patients' decisions and still maintain an adequate level of patients' autonomy. The level of autonomy required for decision making to be truly shared. This means that 'there must be agreement between participants regarding all aspects of clinical choice. Simply engaging in the process of consultation does not constitute sharing decisions.' [58].

Munthe et al. [45] draw attention to the problem, that in PCC and SDM, the key component is continuity, and therefore adherence in relation to mutually agreed treatment plan may not be secured by one agreement. This means that the treatment plan may be actualized during the new round of SDM, leading to a new agreement where issues making the patient non-adherent are taken into consideration to secure future adherence. However, maybe further from the optimal, based on EBM, treatment plan. This raises the question of to what extent patients not having deep clinical knowledge may take responsibility for their treatment? Whether at the end patients would not regret their own decisions and blame professionals for not convincing them to the EBM treatment plan. This is a very important issue taking into account above mentioned limitations regarding the abilities to comprehend patients' narratives by professionals and professional recommendations by patients.

Tonelli and Sullivan [58] claim that in SDM professionals and a patient have to choose the same thing for the patient. When there is a discrepancy, it could mean that the professionals do not understand the patient or that the patient does not understand what the professionals are trying to convey. Within a medical relationship, such discrepancy should be an invitation to a further examination of the knowledge and dialog since in SDM, it is not sufficient to accept the patient's choice. Professionals have to really understand and accept the patient's rationale for the choice. According

to [58], when there is intractable disagreement, it should lead to the end of the medical relationship between the patient and professionals.

5.5 Conclusion

This chapter examined shared-decision (SDM) models as an approach to personcentered care (PCC). SDM concept could be recognised in three levels (micro, meso, macro) of implementation that we introduced.

Multi-criteria decision analysis (MCDA) methods could be used effectively to facilitate SDM in practice, and different techniques in the recent publications were presented. The chapter concluded with an overview of the benefits and barriers in shared-decision implementation in the healthcare system. SDM can be closely associated with core PCC routines of creating, working, and maintaining a physician-patient/person partnership.

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