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Shared decision making: Concepts, evidence, and practice

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ABSTRACT

Objective: Shared decision-making (SDM) is advocated as the model for decision-making in preference-sensitive decisions. In this paper we sketch the history of the concept of SDM, evidence on the occurrence of the steps in daily practice, and provide a clinical audience with communication strategies to support the steps involved. Finally, we discuss ways to improve the implementation of SDM.

Results: The plea for SDM originated almost simultaneously in medical ethics and health services research. Four steps can be distinguished: (1) the professional informs the patient that a decision is to be made and that the patient's opinion is important; (2) the professional explains the options and their pros and cons; (3) the professional and the patient discuss the patient's preferences and the professional supports the patient in deliberation; (4) the professional and patient discuss the patient's wish to make the decision, they make or defer the decision, and discuss follow-up. In practice these steps are seen to occur to a limited extent.

Discussion: Knowledge and awareness among both professionals and patients as well as tools and skills training are needed for SDM to become widely implemented.

Practice Implications: Professionals may use the steps and accompanying communication strategies to implement SDM.

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1. Background

Shared decision making (SDM) is increasingly advocated as the preferred model to engage patients in the process of deciding about diagnosis, treatment or follow-up when more than one medically reasonable option is available. The phrase "sharing of decision making" was used for the first time in 1972 by Veatch [1], in his paper "Models for Ethical Medicine in a Revolutionary Age: What physician-patient roles foster the most ethical relationship?" Yet, the concept SDM started did not appear in the research literature till 1997 with the landmark paper of Charles et al. [2]: "Shared Decision making in the medical encounter: what does it mean? (Or: it takes at least two to tango)". Clinical acceptance of the concept is of even more recent date. Today, key figures such as patient representatives, policy makers, hospitals, and health insurers worldwide advocate the principles of SDM as the ideal for decision making.

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Despite professionals indicating that they consider it important to share decisions with patients [3,4], SDM seems to be applied in daily practice to a limited extent only [5,6]. Several steps have to be taken before one can truly speak of SDM [7,8], and apparently people hold conflicting views on what these steps entail. In this paper we discuss, first, the history of the term and the concept of SDM, and show how two different lines of thinking lead to the same conclusion: that for certain decisions SDM should be the norm. Secondly, we divide the SDM process into four major steps. For each step we will discuss the evidence for its implementation in clinical practice. To facilitate such implementation, we next provide simple communication strategies for these steps. Finally, we reflect on 'where we stand' and what major issues are still open for study.

2. Two lines of thinking that support the plea for SDM

2.1. Ethics

The first and most obvious line of thinking that leads people to advocate SDM arose in ethics. In 1972, Veatch discussed four models of the professional-lay relationship in the context of ensuring people's right to health care [1]. Following both the biological revolution ('cure of disease is possible') and the social revolution ('all

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men are to be treated equally'), healthcare had become "a human right, no longer a privilege limited to those who can afford it" (p. 5). Veatch pleaded for a contractual model in which "there is a real sharing of decision making". Where the paternalistic model had thrived on the moral principles of benefitting and doing no harm to the patient, Veatch added patients' freedom and dignity, as well as justice, i.e., a fair distribution of health services. The approach of Beauchamp and Childress, published in 1979 [9] and still taught in medical schools today, similarly emphasizes these four themes: beneficence, non-maleficence, patient autonomy, and justice. In the 1980s increasing emphasis was put on patient autonomy, as reflected in, e.g., the patients' rights movement and the change of the informed consent standard from physician-based to patientbased [10]. Additionally, in the context of these ethical discussions of ideals for the physician-patient relationship, Emanuel and Emanuel [10] in 1992 published their seminal paper on 'Four Models of the Physician-Patient Relationship'. They discussed different understandings of the physicians' obligation and role, the role of patients' values, and the conception of patients' autonomy. These are still relevant to the discussion of SDM today. Veatch had described the paternalistic and informative models, referring to them as priestly and engineering respectively. In between these two Emanuel and Emanuel saw a deliberative model, in which physicians persuade patients of 'the most admirable health-related values', and an interpretative model, in which patients need help in elucidating their values. In the deliberative model, physicians provide information to help patients understand their situation and agree with a recommendation, while the weighing of benefits and harms lies with the doctor. In contrast, in the interpretative model patients' values take precedence over those of the physician. Emanuel and Emanuel described the arising SDM model as an "informative model under a different label" (p. 2224). They saw a similar fact-value distinction in SDM as in the informative model: facts provided by the physician combined with values from the patient. Yet, they acknowledged that others argue for an SDM model

that is more mutual, and in which dialogue is used to help patients

understand their values and objectives. This latter model is more

clearly in line with the current thinking about SDM as will be

2.2. Practice variation

described below.

In the 1990s, Jack Wennberg started to link his work on clinical practice variation to SDM, albeit not under this term. Already in the early 1970s [11], he documented the geographic variation in health care use in the USA. He showed that practice was supplydriven rather than evidence-based, indicating that physicians'preferences play a large role in decision-making. This work led him to distinguish effective from preference-sensitive decisions (Wennberg, in [12]). In effective decisions there is sufficient evidence on benefit-harm ratios, and harms are small compared to benefits. In these cases, there is one optimal strategy. In preference-sensitive decisions, there is no best strategy, since either the evidence on the benefit-harm ratio is insufficient, or the ratio depends on (patients') values. Practice variation was thus an indicator of the preference-sensitive nature of decisions: practice seemed determined by physicians' preferences or practice style factors rather than consumer or population related factors [13]. In the early 1990s, Wennberg therefore proposed to use SDM programs for patients, to counter unwarranted practice variation [14]. Possibly this could also reduce health care costs. Indeed, the emerging field of patient decision aids research later showed for major elective invasive surgery, prostate-specific antigen screening, or menopausal hormone therapy, that if patient decision aids were used to support patients appropriately and in a neutral way, fewer patients chose to undergo these interventions [15]. This subsequently led to the promotion of SDM as a vehicle to reduce health care costs, particularly by policy makers [16]. Even though a later review showed that the evidence on cost savings is not clear-cut [17,18], it led to SDM attracting more widespread attention.

3. Shared decision making: concepts and definitions

Thus, SDM had been put on the agenda via two different fields. medical ethics and health services research. The major breakthrough came with two papers by Charles and colleagues [2,19] that tried to elucidate the concept, "(. . .) for it is by no means clear what shared decision making really means or the criteria by which to judge what falls within or outside the boundaries of this model." [2] They described an important aspect that distinguishes SDM from previous models of treatment decision making, the two-way exchange of not only information but also treatment preferences. Indeed, research had begun to show that patients' preferences vary widely, are often different from physicians' preferences, and cannot be adequately predicted by patient characteristics. New in their model was also that both patient and physician agree with the final treatment decision, which need not necessarily have been the physician's preferred option. Charles et al. revised their 1997 framework in 1999, to explicitly include three steps in the treatment decision making process: information exchange, deliberation, and making a decision. They also provide a dynamic view of decision making, in which the approach adopted at the outset of a medical encounter may change as the interaction evolves. Following the now classical papers, the term SDM was evoked frequently but loosely in teaching and research. This led Makoul and Clayman [7] and Moumjid et al. [20] to almost simultaneously provide systematic literature reviews of definitions and models, in which they showed that there was no shared definition of SDM. Only the elements options and patient preferences appeared in more than half of the definitions [7]. Makoul and Clayman identified the following essential elements of SDM in the most prominent conceptual definitions: (1) define or explain problem; (2) present options; (3) discuss pros and cons (benefits/risks/costs); (4) assess patients' values or preferences; (5) discuss patient ability or selfefficacy; (6) provide doctor knowledge or recommendations; (7) check or clarify understanding; (8) make or explicitly defer decision and (9) arrange follow-up. Since then, authors have elaborated and simplified the model of SDM, mostly for educational purposes (e.g., [8,21]). Elwyn and colleagues [21] e.g., assigned the various steps to the respective phases: (1) choice talk, making sure that patients know that reasonable options are available, (2) option talk, the step of providing more detailed information about options, and (3) decision talk, the step of considering preferences and deciding what is best. Despite the widespread reference made to these phases, we prefer to use four steps. Particularly the third phase (Decision talk) contains two quite distinct processes that we feel should be clearly laid out as two steps. We therefore distinguish the following easy to memorize steps:

- 1. The professional informs the patient that a decision is to be made and that the patient's opinion is important;
- 2. The professional explains the options and the pros and cons of each relevant option
- 3. The professional and patient discuss the patient's preferences; the professional supports the patient in deliberation
- The professional and patient discuss patient's decisional role preference, make or defer the decision, and discuss possible follow-up.

In the next two sections we will first describe the evidence of the occurrence of the steps in clinical practice, and next provide an

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educational outline of the steps and provide communication suggestions for professionals for the clinical encounter. We generally refer to treatment decisions, but the same process may obviously hold for decisions about diagnostic testing or follow-up. Further, we speak of professionals, implying health care

professionals, since increasingly not only physicians are involved in SDM, but also others, e.g., practice nurses.

4. Are the four SDM steps implemented in clinical practice?

To date little evidence is available on the effects of SDM on patient outcomes, particularly health outcomes [22]. One reason for this absence of evidence is the lack of good measurement instruments, particularly to assess the actual realization of SDM [23,24]. Research on methods to assess SDM appeared relatively late. It showed that there is little agreement between patient-, professional-, and observer-based reports on the occurrence of SDM [25]. Earlier studies had mostly used the SDM-Q questionnaires for doctor [26] and patient [27], respectively [28]. Observer-based analysis of audio- or consultations became a valuable contribution to evaluate whether and how SDM is applied in practice. Since this entails a cumbersome process, few studies have been published to date, and even fewer have long follow-up to assess health outcomes. Yet, the studies available all show a limited use of SDM in practice.

Most studies so far that provide an indication of the prevalence of SDM have used the OPTION scale [29,30]. Even though this scale was not developed to assess SDM and focuses solely on the professional's behaviour, it captures professionals' attempts to involve patients, and thereby reflects some key aspects of SDM. The review of Couët et al. [5] of studies in which the OPTION scale was used, thereby provides insight into the occurrence of professional-related aspects of SDM. Remarkably, the review shows that in many studies the behaviour necessary on the part of the professional in practicing SDM was not observed at all, and in studies in which it was observed, it was only performed perfunctorily.

For step 1, Couët et al. showed that only in five out of 16 studies equipoise was explained. Other research shows that presenting the decision as a fact and not mentioning alternative options are common behaviours [31,32]. An alternative option, or even 'doing nothing', may come only into view only if patients are not eligible for a certain treatment [33]. We showed in a study on adjuvant cancer treatment that in only 3% of consultations it was stated that a (preference-sensitive) decision needed to be made. In none of 100 consultations the option of no adjuvant therapy was discussed [6].

For step 2, research overwhelmingly shows that patients wish to know more than physicians think [34,35]. Patients often are not aware of the options, i.e., do not experience a treatment choice. Also, there is large variation in what treatment outcomes are mentioned [4,36], major risks go undisclosed [4,36,37], patients often do not realise that risks are involved, and feel uninformed [38–40]. Further, information may be used to implicitly steer the patient towards a professional-favoured strategy, e.g., by presenting relative risks only [41] ("with radiotherapy you have half the risk of a recurrence"), or by presenting harms of treatment after the decision has been made [32].

Step 3, assessing patient preferences and supporting the deliberation process, is not common either. Couët et al. showed that only in one out of 17 studies patient preferences were established. Knops et al. [37] showed that in only a quarter of patients (23%) the surgeon elicited patient preferences for aneurysm surgery. Similarly, for adjuvant radiotherapy decisions in rectal cancer, analyses of audiotaped consultations showed that radiation oncologists explicitly gave room to voice an alternative

treatment preference or to make a choice to only a third (31%) of patients [42]. Analyses of the integration of patient preferences showed that in these radiotherapy decisions, treatment preferences were explicitly considered in the decision in less than half (41%) of the cases [42].

We are not aware of research in which deliberation was investigated explicitly. Pieterse et al. [43] showed in early-stage prostate cancer treatment decision making, that radiation oncologists failed to request patients' evaluations, ascertain whether patients' evaluations were well-informed, or explore them. These behaviours would help patients in forming more stable preferences and would benefit patients in the long run. Similarly, in a survey on endometrial cancer decision making, Kunneman et al. [44] showed that the majority of irradiated patients indicated that they had lacked room to think about benefits and harms of vaginal brachytherapy (42%), and give their opinion on benefits and harms (43%).

For the fourth, final step, establishing the patient's decisional role preference, making the decision, and discussing possible follow-up, Couët et al. showed that preferred involvement was not seen in any out of 18 studies. However, this may often be left implicit. Conversely, Couët et al. showed that indicating a need to review or defer the decision was often performed: this was the third most consistently observed behaviour, in 69% of studies.

Thus, the steps to be taken in SDM are seen to a limited extent only in daily clinical practice. We explain these steps in more detail in the next section and, to facilitate their use, suggest phrases that may be used in each step to support the SDM process in separate boxes [8].

5. Shared decision making: elaboration of the steps and communication propositions

Clinicians may think that the process described below is lengthy. Indeed, the evidence so far shows a small increase in consultation time if time is invested in SDM [15,42]. Yet, if taken carefully, the steps may lead not only to decisions that better fit the individual patient and as a result provide more satisfaction, but also to better professional-patient relations, fewer repeat consultations, fewer requests for second opinions, and, in the long term better treatment adherence and outcomes.

5.1. Applying the steps

Step 1. Professional informs patient that decision is to be made and patient's opinion is important

Patients may expect the professional to be clear about the preferred option, believing that "the doctor knows what is good for me". Yet, the best management of health problems is not necessarily evident. Evidence for effective action may be either lacking or weak. Also, clear options may be available that differ in terms of the outcomes. The choice for such outcomes will then depend on the values attached to them and the weighing thereof. In such cases one can speak of a situation of 'equipoise'. Values are personal and can therefore not result from the considerations of professionals only. Despite patients indicating that "(. . .) doing nothing is no choice" [45], after good information provision, watchful waiting or active surveillance can sometimes be the preferred choice. In both situations, i.e., lack of evidence and equipoise, the decision is thus preference-sensitive [12]. As a first step to SDM, the professional thus makes explicit that the decision is preference-sensitive by explaining that a choice is to be made and that this choice will depend on what is important to the

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Box 1.: Step 1. Formulations that may help to explain equipoise

"Now that it is clear what you have, I must tell you that there are different medical options possible. They each have their pros and cons. Therefore, we will have to see what is best for you and then decide about the further steps to be taken."

"As you may know, we have different approaches to treat your condition. We are not sure what the best one is for you. They have varying outcomes. And, people differ in what they think is important to them. Therefore, we need to discuss what is important to you and, as a result, which approach would be best for you."

"Actually, this is a problem that unfortunately we as doctors do not know everything about yet. Therefore, it is even more important that we make this decision together, on the basis of the little that is known."

Step 2. Professional explains the options and the pros and cons of each option

Secondly, the professional explains in a neutral way what the options are and to what extent they have advantages and disadvantages, i.e., their benefits and harms. It is important to consider a number of issues: (1) What information is relevant? (2) What prior knowledge does the patient have? (2) Is information complete? (3) How is risk information conveyed? (4) Does the patient understand the information? [46]

As regards risk communication, Zipkin et al. [47] reviewed the literature, and provided the following recommendations. It is better to use percentages or natural frequencies, rather than chance words. It was shown that risk perceptions of patients vary more strongly for chance words than for frequencies [48–50]. They advise the use of absolute rather than relative risks, for the latter tend to steer a patient towards a decision. Also, Numbers Needed to Treat are difficult to understand for patients and should be avoided. Further, visual aids may help patients, particularly icon arrays (faces or stick figures) for small probabilities, or bar charts for larger ones [47].

It is often considered difficult to check understanding as the professional feels it may be seen by the patient as an examination. It can be made less stressful for patients when prefaced with a statement about the professional wanting to check on his or her own skills. Also, acknowledging that information might have been overwhelming for the patient makes the checking of understanding more acceptable, as it can also help the patient to accept the reason for the enquiry [51].

A pitfall in communicating benefits and harms of treatment is that of implicit normativity: presenting the information in such a way that the patient is implicitly steered towards one specific option [31,32]. The professional may, consciously or unconsciously, present one option as the logical one to choose, by, e.g., the framing of the outcomes and the probabilities. Other examples of 'salesman' [32] techniques are presenting treatment as an authorized 'we' decision, selectively emphasizing the benefits or harms of treatment, or downplaying the negative impact of treatment.

Step 3. The discussion of patient preferences and supporting of deliberation

Patients often do not have clear preferences at the outset [52,53]. These then need to be formed in the process of deliberation with the professional. For this reason we use one step here where others might distinguish the two steps of preference elicitation and deliberation. In the process of balancing the pros and cons of the options, it is essential to explicitly raise the issue of the relevance of outcomes to the patient. In this part of the consultation the professional takes an explorative stance and ideally poses open questions. "Values clarification exercises" have also been shown to support patients in forming preferences, but these are generally used outside of the consultation, e.g., in patient decision aids [15]. The comparison of the pros and cons of options may be facilitated in the consultation by presenting options sideby-side in table format [54,55]. In this way patients are helped in weighing the options in the process of deliberation [56,57]. An example of this is seen in the Option Grids [58].

Box 2. : Step 2. Formulations that may help to explain options and pros and cons

Separate options and outcomes i.e., first mention the options explicitly:

"There are two treatment options for your condition. One is \dots (X), the other is. \dots (Y). Let me first explain to you what the pros and cons of treatment X are."

To explain risks or chances

"The two options that may be applicable to you are X and Y. Have you heard about these already? If so, let us see what you know, and then discuss what the effects and side effects are."

"Out of 10 people who are in the same situation as you are, 3 will experience" (rather than 30%)

"You can understand that this does not necessarily happen to everyone who undergoes treatment. As far as we know from the literature, out of 100 persons that take this medication, 20 may suffer from bleeding." (rather than 20%). Unfortunately we cannot tell beforehand whether you will be among those who will suffer from this, or among those who will not."

For risk information to be neutral, use both a positive and a negative frame:

"The chances that you will survive for five years with this treatment is 4 out of 5. In other words, 1 of 5 patients like yourself will not be alive after five years."

"It should be mentioned that there are some serious risks attached to this operation. Unfortunately, two patients out of a hundred undergoing the surgery will die as a result of it. This means at the same time that 98 of them will survive."

Check understanding [46]

"So that I can make sure that I've done a good job of explaining things to you, can you tell me what you are taking away from this discussion?"

"I know I've given you a lot of information at once, but it is important that the information was clear".

Box 3.: Step 3. Formulations that may help to discuss values and support deliberation

- "Hearing what I just told you, are there any thoughts, concerns or worries that immediately come to mind?"
- "Thinking about this decision and what we just discussed, what are important aspects for you to consider?"
- "What other things do you think are relevant for the choice to be made?"
- "What weighs heavily for you when you have to make this decision?"
- "How do the benefits of both options compare? And how do the harms compare?"

Box 4. : Step 4. Formulations that may help to enquire after the patient's wish to make the final decision and may help make the decision

Patients wish to make the decision

- "We have seen what is important for you. How would you now like to make the decision?"
- "Some people like to make the decision themselves, once all pros and cons have been considered and weighed. Others rather have their doctor make the eventual decision. Still, others rather do it together. How is that for you?"
- "We can make a decision together now, but you might also prefer to have some time to think about things or talk to others, and make it on your own or with your family. Or you can come back to discuss it in another consultation. What would you think is the best for you?"

Final decision

- "Now, do you already know what decision you want to make?"
- "Now if I understand you well, you are inclined to choose "
- "Taking things together, I think that you would be best off if we decided to"

Step 4. Discussing the patient's wish to make the decision, making the decision, and discussing follow-up

After it has been established what outcomes are important to the patient, and preferences may have been formed in the deliberation process, one can move to the actual decision making phase. Patients differ in their wish to make the decision themselves or rather have the professional take the responsibility for the eventual decision. The patient's position may sometimes be obvious and not have to be established. In other cases, the wish to be involved, or not, may need to be addressed explicitly. We caution against asking patients for their role preference upfront in the consultation, as has been proposed elsewhere [59]. If patients have not been made aware first that a decision is to be made and what the options and the benefitharm trade-offs are, they may not realize that their preferences count, and what considerations are important for them [60]. Subsequently they may wrongly defer the decision to the professional. In a study in oncology, many patients who upfront indicated the wish for the professional to decide were found to prefer to decide themselves after having been presented with information on the pros and cons of the options [61]. When the patient still prefers to hand over the decision, and the professional and patient have gone through steps 1 to 3, the professional now knows what preferences for treatment outcomes should be taken into account when proposing the preferred approach. We still speak of SDM in that case.

Once the decisional roles are apparent, the decision can be made. Ideally, the professional summarizes what has been addressed so far. He or she can then ask for the patient's opinion or suggest what (s) he understands from the patient's reactions so far. Sometimes patients need time to think things over or want to discuss them with others, and a second appointment may have to be made. If not, the decision can be made and professional and patient agree on how to proceed, e.g., by prescribing treatment, referring for it, or planning a follow-up consultation.

6. Discussion and conclusion

6.1. Discussion

In 2015, over 40 years after the first mentioning of the term SDM, and over 15 years after Charles et al.'s publications, SDM has finally reached the implementation agenda and become the target of educational programs in many countries around the world. Yet, there is still little evidence for its occurrence in clinical practice. Therefore, there is on-going debate on how to improve implementation, through training and tools, both for professionals and patients [62,63]. A number of suggestions have been made to support such implementation.

First, in some countries hospitals have started to implement the Ask 3 questions approach, in an attempt to encourage SDM. This expressly invites patients who attend outpatient clinics to ask questions to their professionals [64]. Such encouragement is needed, for research shows that patients often do not dare speak up for fear of being labelled as difficult [65,66]. Further, patients not only are hesitant to ask questions, but often are not aware of the primary role they can have in decision making, particularly for preference-sensitive decisions.

Secondly, patient decision aids, i.e., tools that support patients in SDM by providing information and help in the process of forming a preference, are increasingly published and were shown to improve knowledge and expectations, improve patient involvement in decision making, decrease decisional conflict and the number of postponed decisions, and improve the agreement between patient choice and patient values [15] (see e.g. http://decisionaid.ohri.ca/AZinvent.php for an international inventory of decision aids). Patient decision aids are useful and supplement SDM practice but cannot replace the conversation in clinical encounters.

Third, most of the research presented above refers to physicians, but increasingly other health care professionals, e.g., nurses, are involved in decision making, and play a supportive role in helping patients form preferences and deliberate about the pros

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and cons of treatment. In the Netherlands, e.g., patients may have an appointment with a breast cancer nurse following their initial visit with the surgeon but before the decision about surgery is made. In such consultations, more time is provided for information exchange, questions, and deliberation. Subsequently patients are better empowered for an SDM process with their surgeon. Such approach is promising, since it takes part of the time pressure off the consultation with the medical specialist.

Fourth, medical as well as nursing curricula have started to incorporate SDM into their communication skills programs. Indeed skills training for residents as well as specialists is starting to bud, but mostly so in Western countries such as North-Western Europe, Canada, the US, and Australia [67]. Elsewhere, some groups are active in this field, but the efforts seem incidental so far [68].

Fifth, however, we do not just need to train skills, but also to raise knowledge and awareness. The concept is simple, but as was shown, not easily implemented. Whether this is a matter of knowledge, attitudes, or skills will differ per country, but probably none of these three is at a sufficient level yet anywhere for sustainable implementation. Concerted action is therefore needed. First, professionals can become increasingly aware of the preference-sensitive nature of many decisions. To support this, guideline developers are advised to make explicit in the guidelines which assumptions about values and preferences underlie their recommendations [69]. This will help professionals to recognize decisions as preference-sensitive [70]. Further, professionals and policy makers alike need to be convinced of SDM's relevance. The strongest motivation derives from an ethical viewpoint, as described above, but obtaining and disseminating evidence will also support this process. A recent systematic review of 50 empirical studies [22] showed that the SDM tends to result in positive affective cognitive outcomes such as increased satisfaction in the majority of studies. Studies reporting behavioural measures, such as the treatment decision or adherence, did also yield positive results in 37% of cases, and self-reported symptoms, quality of life or mental function in 43%. Almost no (3%) negative results were encountered. Further research may indicate that, depending on the field of medicine, it may also lead to reduced costs, as was shown for elective surgery (orthopaedic surgery, surgery for Benign Prostatic Hyperplasia), PSA screening and some forms of medication [13,15], but can also be expected in a field like end-of-life care [71].

Recently, it was questioned whether patients' autonomy should not be reined in, and the use of SDM limited, given the evidence from psychology showing that human decision making is subject to strong emotions and biases, and rationality bounded [72,73]. This evidence indeed arose as far back as the mid-20th century, but has indeed been a strong driver for the field of patient decision aids. Bounded rationality is in fact a reason to support SDM, both in patients and in professionals, who are not immune to rationality biases either [74]. If appropriately executed, it will help patients improve their rationality, by helping them to carefully consider what awaits them, and what their considerations and priorities are. Thus with SDM decisions taken eventually will likely be better informed and congruent with patients' values and preferences.

6.2. Conclusion

In conclusion, SDM is the preferred approach particularly relevant for preference-sensitive decisions. It is likely to lead to better professional-patient relationships, better decisions and better outcomes. Patients, becoming increasingly assertive, prefer this approach. It has been advocated for ethical reasons for over 40 years but nevertheless, is still not widely implemented in clinical practice. Various strategies can encourage SDM, as

proposed. Importantly, educational efforts should not only focus on skills training, but also on knowledge and attitudes.

6.3. Practice implications

The four-step approach described here, with its accompanying communication strategies may help professionals in their attempt to share decisions with patients. As stated so aptly by Hoffmann and Montori: SDM is "the intersection of patient-centered communication skills and EBM, in the pinnacle of good patient care [75].

Conflicts of interest

No conflicts of interest declared.

Author's contribution

All authors have individually contributed to the article: in drafting the article and revising it critically for important intellectual content and have approved the final version submitted.

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References

- [1] R.M. Veatch, Models for ethical medicine in a revolutionary age. What physician-patient roles foster the most ethical relationship? Hastings Cent. Rep. 2 (1972) 5–7.
- [2] C. Charles, A. Gafni, T. Whelan, Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango), Soc. Sci. Med. 44 (1997) 681–692.
- [3] A.H. Pieterse, M.C. Baas-Thijssen, C.A. Marijnen, A.M. Stiggelbout, Clinician and cancer patient views on patient participation in treatment decision-making: a quantitative and qualitative exploration, Br. J. Cancer 99 (2008) 875–882.
- [4] H.S. Snijders, M. Kunneman, B.A. Bonsing, A.C. De Vries, R.A. Tollenaar, A.H. Pieterse, A.M. Stiggelbout, Preoperative risk information and patient involvement in surgical treatment for rectal and sigmoid cancer, Colorectal Dis. 16 (2014) 043–049.
- [5] N. Couët, S. Desroches, H. Robitaille, H. Vaillancourt, A. Leblanc, S. Turcotte, G. Elwyn, F. Légaré, Assessments of the extent to which health-care providers involve patients in decision making: a systematic review of studies using the OPTION instrument, Health Expect. (March) (2013), doi:http://dx.doi.org/10.1111/hex.12054 [Epub ahead of print].
- [6] M.A. Kunneman, L. Ten Hove, A.M. Stiggelbout, J.C.J.M. De Haes, E.M.A. Smets, E.G. Engelhardt, A.H. Pieterse, Reason for encounter: a missed opportunity for shared decision making, Med. Decis. Making 35 (2015) E59.
- [7] G. Makoul, M.L. Clayman, An integrative model of shared decision making in medical encounters, Patient Educ. Couns. 60 (2006) 301–312.
- [8] A.M. Stiggelbout, T. Van der Weijden, M.P.T. De Wit, D. Frosch, F. Légaré, V.M. Montori, L. Trevena, G. Elwyn, Shared decision making: really putting patients at the centre of health care, Br. Med. J. 344 (2012) e256, doi:http://dx.doi.org/10.1136/bmj.
- [9] T.L. Beauchamp, J.F. Childress, Principles of Biomedical Ethics, Oxford University Press, Oxford, 1979.
- [10] E.J. Emanuel, L.L. Emanuel, Four models of the physician-patient relationship, J. Am. Med. Assoc. 267 (1992) 2221–2226.
- [11] J.E. Wennberg, Forty years of unwarranted variation—and still counting, Health Policy 114 (2014) 1–2.
- [12] A.M. O'Connor, F. Légaré, D. Stacey, Risk communication in practice: the contribution of decision aids, Br. Med. J. 327 (2003) 736–740.
- [13] J.E. Wennberg, Dealing with medical practice variations: a proposal for action, Health Aff. 3 (1984) 6–32 Millwood).
- [14] J.E. Wennberg, B.A. Barnes, M. Zubkoff, Professional uncertainty and the problem of supplier-induced demand, Soc. Sci. Med. 16 (1982) 811–824.
- [15] D. Stacey, F. Légaré, N.F. Col, C.L. Bennett, M.J. Barry, K.B. Eden, M. Holmes-Rovner, H. Llewellyn-Thomas, A. Lyddiatt, R. Thomson, L. Trevena, J.H. Wu, Decision aids for people facing health treatment or screening decisions, Cochrane Database Syst. Rev. 1 (January) (2014) CD001431.
- [16] E. Oshima Lee, E.J. Emanuel, Shared decision making to improve care and reduce costs, N. Engl. J. Med. 368 (2013) 6–8.
- [17] T. Walsh, P.J. Barr, R. Thompson, E. Ozanne, C. O'Neill, G. Elwyn, Undetermined impact of patient decision support interventions on healthcare costs and

ŝ

A.M. Stiggelbout et al./Patient Education and Counseling xxx (2015) xxx-xxx

- savings: systematic review, Br. Med. J. 348 (January) (2014) g188, doi:http://dx. doi.org/10.1136/bmj.g188.
- [18] S.J. Katz, S. Hawley, The value of sharing treatment decision making with patients: expecting too much, J. Am. Med. Assoc. 310 (2013) 1559–1560.
- [19] C. Charles, A. Gafni, T. Whelan, Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model, Soc. Sci. Med. 49 (1999) 651–661.
- [20] N. Moumjid, A. Gafni, A. Brémond, M.O. Carrère, Shared decision making in the medical encounter: are we all talking about the same thing, Med. Decis. Making. 27 (2007) 539–546.
- [21] G. 21Elwyn, D. Frosch, R. Thomson, N. Joseph-Williams, A. Lloyd, P. Kinnersley, E. Cording, D. Tomson, C. Dodd, S. Rollnick, A. Edwards, M. Barry, Shared decision making: a model for clinical practice, J. Gen. Intern. Med. (2012) 1361–1367 2.
- [22] L.A. Shay, J.E. Lafata, Where is the evidence? A systematic review of shared decision making and patient outcomes, Med. Decis. Making 35 (2015) 114–131.
- [23] I. Scholl, L.M. Koelewijn-van, K. Sepucha, et al., Measurement of shared decision making—a review of instruments, Z. Evid. Fortbild. Qual. Gesundhwes. 105 (2011) 313–324.
- [24] J. Kasper, C. Heesen, S. Kopke, et al., Patients' and observers' perceptions of involvement differ. Validation study on inter-relating measures for shared decision making, PLoS One 6 (2011) e26255.
- [25] J. Kasper, F. Hoffmann, C. Heesen, S. Köpke, F. Geiger, MAPPIN'SDM—the multifocal approach to sharing in shared decision making, PLoS One 7 (4) (2012) e34849.
- [26] I. Scholl, L. Kriston, J. Dirmaier, et al., Development and psychometric properties of the shared decision making questionnaire-physician version (SDM-Q-Doc), Patient Educ. Couns. 88 (2012) 284–290.
- [27] L. Kriston, I. Scholl, L. Holzel, et al., The 9-item shared decision making questionnaire (SDM-Q-9) development and psychometric properties in a primary care sample, Patient Educ. Couns. 80 (2010) 94–99.
- [28] J. Kasper, F. Hoffmann, C. Heesen, S. Köpke, F. Geiger, Completing the third person's perspective on patients' involvement in medical decision-making: approaching the full picture, Z. Evid. Fortbild. Qual. Gesundhwes. 106 (2012) 275–283.
- [29] G. Elwyn, A. Edwards, M. Wensing, K. Hood, C. Atwell, R. Grol, Shared decision making: developing the OPTION scale for measuring patient involvement, Oual. Saf. Health Care 12 (2003) 93–99.
- [30] G. Elwyn, H. Hutchings, A. Edwards, F. Rapport, M. Wensing, W.Y. Cheung, R. Grol, The OPTION scale: measuring the extent that clinicians involve patients in decision-making tasks, Health Expect. 8 (2005) 34–42.
- [31] A.C. Molewijk, A.M. Stiggelbout, W. Otten, H. Dupuis, J. Kievit, Implicit normativity in evidence-based medicine. A plea for integrated empirical ethics research, Health Care Anal. 11 (2003) 69–92.
- [32] O. Karnieli-Miller, Z. Eisikovits, Physician as partner or salesman? Shared decision-making in real-time encounters, Soc. Sci. Med. 69 (2009) 1–8.
- [33] S. Ziebland, A. Chapple, J. Evans, Barriers to shared decisions in the most serious of cancers: a qualitative study of patients with pancreatic cancer treated in the UK, Health Expect. (December) (2014), doi:http://dx.doi.org/10.1111/hex.12319 [Epub ahead of print].
- [34] S.M. Lagarde, S.J. Franssen, J.R. van Werven, E.M. Smets, T.C. Tran, H.W. Tilanus, J.T. Plukker, J.C. de Haes, J.J. van Lanschot, Patient preferences for the disclosure of prognosis after esophagectomy for cancer with curative intent, Ann. Surg. Oncol. 15 (2008) 3289–3298.
- [35] N.B. Janssen, F.J. Oort, P. Fockens, D.L. Willems, H.C. de Haes, E.M. Smets, Under what conditions do patients want to be informed about their risk of a complication? A vignette study, J. Med. Ethics 35 (2009) 276–282.
- [36] M. Kunneman, C.A. Marijnen, T. Rozema, H.M. Ceha, D.A. Grootenboers, K.J. Neelis, A.M. Stiggelbout, A.H. Pieterse, Decision consultations on preoperative radiotherapy for rectal cancer: large variation in benefits and harms that are addressed, Br. J. Cancer 112 (2015) 39–43.
- [37] A.M. Knops, D.T. Ubbink, D.A. Legemate, J.C. de Haes, A. Goossens, Information communicated with patients in decision making about their abdominal aortic aneurysm, Eur. J. Vasc. Endovasc. Surg. 39 (2010) 708–713.
- [38] D.J. Kiesler, S.M. Auerbach, Optimal matches of patient preferences for information, decision-making and interpersonal behavior: evidence, models and interventions, Patient Educ. Couns. 61 (2006) 319–341.
- [39] L. Berman, L. Curry, R. Gusberg, A. Dardik, L. Fraenkel, Informed consent for abdominal aortic aneurysm repair: The patient's perspective, J. Vasc. Surg. 48 (2008) 296–302.
- [40] K.A. Nicolaije, O. Husson, N.P. Ezendam, M.C. Vos, R.F. Kruitwagen, M.L. Lybeert, L.V. van de Poll-Franse, Endometrial cancer survivors are unsatisfied with received information about diagnosis, treatment and follow-up: a study from the population-based PROFILES registry, Patient Educ. Couns. 88 (2012) 427–435.
- [41] M. Kunneman, A.M. Stiggelbout, C.A.M. Marijnen, A.H. Pieterse, Probabilities of benefit and harms of preoperative radiotherapy for rectal: what do radiation oncologists tell and what do patients understand? Patient Educ. Couns. (2015), doi:http://dx.doi.org/10.1016/j.pec.2015.05.009 pii: S0738-3991(15)00230-X. [Epub ahead of print].
- [42] Pieterse, A.H., Kunneman, M., Marijnen, C.A.M., Stiggelbout, A.M., Decision consultations on preoperative radiation in rectal cancer: Limited explicit justification of treatment choice, Oral abstract EACH 2014, Amsterdam, the Netherlands www.each.eu/wp-content/uploads/2015/01/each_Amsterdam_2014_abstracts1.pdf, page 48.

- [43] A.H. Pieterse, I. Henselmans, H.C. De Haes, C.C. Koning, E.D. Geijsen, E.M. Smets, Shared decision making: prostate cancer patients' appraisal of treatment alternatives and oncologists' eliciting and responding behavior, an explorative study, Patient Educ. Couns. 85 (2011) e251–e259.
- [44] M. Kunneman, A.H. Pieterse, A.M. Stiggelbout, R.A. Nout, M. Kamps, L.C. Lutgens, J. Paulissen, O.J. Mattheussens, R.F. Kruitwagen, C.L. Creutzberg, Treatment preferences and involvement in treatment decision making of patients with endometrial cancer and physicians, Br. J. Cancer. 111 (2014) 674–679.
- [45] C. Charles, T. Whelan, A. Gafni, L. Reyno, C. Redko, Doing nothing is no choice: lay constructions of treatment decision-making among women with earlystage breast cancer, Sociol. Health Illness 20 (1998) 71–95.
- [46] H.F. West, W.F. Baile, Tell me what you understand: the importance of checking for patient understanding, J. Support. Oncol. 8 (2010) 216–218.
- [47] D.A. Zipkin, C.A. Umscheid, N.L. Keating, E. Allen, K. Aung, R. Beyth, S. Kaatz, D. M. Mann, J.B. Sussman, D. Korenstein, C. Schardt, A. Nagi, R. Sloane, D.A. Feldstein, Evidence-based risk communicationa systematic review, Ann. Intern. Med. 161 (2014) 270–280.
- [48] A.D. Gurmankin, J. Baron, K. Armstrong, Intended message versus message received in hypothetical physician risk communications: exploring the gap, Risk Anal. 24 (2004) 1337–1347.
- [49] P. Hopwood, A. Howell, F. Lalloo, G. Evans, Do women understand the odds? Risk perceptions and recall of risk information in women with a family history of breast cancer, Community Genet. 6 (2003) 214–223.
- [50] I.M. Lipkus, Numeric, verbal, and visual formats of conveying health risks: suggested best practices and future recommendations, Med. Decis. Making 27 (2007) 696–713.
- [51] H. Baker, R. Crockett, K. Uus, J. Bamford, T. Marteau, Why don't health professionals check patient understanding? A questionnaire-based study, Psychol. Health Med. 12 (2007) 380–385.
- [52] B. Fischhoff, Values clarification –is there anything in there, Am. Psychol. 46 (1991) 835–847.
- [53] A.H. Pieterse, M. de Vries, M. Kunneman, A.M. Stiggelbout, D. Feldman-Stewart, Theory-informed design of values clarification methods: a cognitive psychological perspective on patient health-related decision making, Soc. Sci. Med. 77 (2013) 156–163.
- [54] D. Feldman-Stewart, M.D. Brundage, L. Van Manen, O. Svenson, Patient-focussed decision-making in early-stage prostate cancer: insights from a cognitively based decision aid, Health Expect. 7 (2004) 126–141.
- [55] G.A. Sundström, Information search and decision making: the effects of information displays, in: A.A. Montgomery, O. Svenson (Eds.), Process and Structure in Human Decision Making, John Wiley & Sons, Chichester, 1989, pp. 209–223.
- [56] R. Dhar, The effect of decision strategy on deciding to defer choice, J. Behav. Decis. Making 9 (1996) 265–281.
- [57] S.M. Nowlis, I. Simonson, Attribute-task compatibility as a determinant of consumer preference reversals, J. Mark. Res. 34 (1997) 205–218.
- [58] G. Elwyn, A. Lloyd, N. Joseph-Williams, E. Cording, R. Thomson, M.A. Durand, A. Edwards, Option Grids shared decision making made easier, Patient Educ Couns. 90 (2013) 207–212.
- [59] C.H. Braddock 3rd, K.A. Edwards, N.M. Hasenberg, T.L. Laidley, W. Levinson, Informed decision making in outpatient practice: time to get back to basics, JAMA 282 (1999) 2313–2320.
- [60] R. Say, M. Murtagh, R. Thomson, Patients' preference for involvement in medical decision making: a narrative review, Patient Educ. Couns. 60 (2) (2006 Feb) 102–114.
- [61] J.J. van Tol-Geerdink, P.F. Stalmeier, E.N. van Lin, E.C. Schimmel, H. Huizenga, W. A. van Daal, J.W. Leer, Do prostate cancer patients want to choose their own radiation treatment, Int. J. Radiat. Oncol. Biol. Phys. 66 (2006) 1105–1111.
- [62] F. Légaré, G. Elwyn, M. Fishbein, P. Frémont, D. Frosch, M.P. Gagnon, D.A. Kenny, M. Labrecque, D. Stacey, S. St-Jacques, T. van der Weijden, Translating shared decision-making into health care clinical practices: proof of concepts, Implement. Sci. 3 (2008) 2.
- [63] F. 63Légaré, D. Stacey, S. Turcotte, M.J. Cossi, J. Kryworuchko, I.D. Graham, A. Lyddiatt, M.C. Politi, R. Thomson, G. Elwyn, N. Donner-Banzhoff, Interventions for improving the adoption of shared decision making by healthcare professionals, Cochrane Database Syst. Rev. 9 (September) (2014) CD006732.
- [64] H.L. Shepherd, A. Barratt, L.J. Trevena, K. McGeechan, K. Carey, R.M. Epstein, et al., Three questions that patients can ask to improve the quality of information physicians give about treatment options: A cross-over trial, Patient Educ. Couns. 84 (2011) 379–385.
- [65] D.L. Frosch, S.G. May, K.A. Rendle, C. Tietbohl, G. Elwyn, Authoritarian physicians and patients' fear of being labeled 'difficult' among key obstacles to shared decision making, Health Aff. (Millwood) 31 (2012) 1030–1038.
- [66] I. Henselmans, M. Heijmans, J. Rademakers, S. van Dulmen, Participation of chronic patients in medical consultations: patients' perceived efficacy, barriers and interest in support, Health Expect. (May) (2014), doi:http://dx.doi.org/ 10.1111/hex.12206 [Epub ahead of print].
- [67] F. Légaré, N. Moumjid-Ferdjaoui, R. Drolet, D. Stacey, M. Härter, H. Bastian, M.D. Beaulieu, F. Borduas, C. Charles, A. Coulter, S. Desroches, G. Friedrich, A. Gafni, I. D. Graham, M. Labrecque, A. LeBlanc, J. Légaré, M. Politi, J. Sargeant, R. Thomson, Core competencies for shared decision making training programs: insights from an international, interdisciplinary working group, J. Contin. Educ. Health Prof. 33 (2013) 267–273.
- [68] C.J. Ng, P.Y. Lee, Y.K. Lee, B.H. Chew, J.P. Engkasan, Z.I. Irmi, N.S. Hanafi, S.F. Tong, An overview of patient involvement in healthcare decision-making: a

A.M. Stiggelbout et al./Patient Education and Counseling xxx (2015) xxx-xxx

- situational analysis of the Malaysian context, BMC Health Serv. Res. 13 (11) (2013) 408.
- [69] J. Andrews, G. Guyatt, A.D. Oxman, P. Alderson, P. Dahm, Y. Falck-Ytter, M. Nasser, J. Meerpohl, P.N. Post, R. Kunz, J. Brozek, G. Vist, D. Rind, E.A. Akl, H.J. Schunemann, GRADE guidelines: 14. Going from evidence to recommendations: the significance and presentation of recommendations, J. Clin. Epidemiol. 66 (2013) 719–725.
- [70] T. Van der Weijden, A. Boivin, J. Burgers, H.J. Schunemann, Elwyn G., Clinical practice guidelines and patient decision aids. An inevitable relationship, J. Clin. Epidemiol. 65 (2012) 584–589.
- [71] J.S. Temel, J.A. Greer, A. Muzikansky, E.R. Gallagher, S. Admane, V.A. Jackson, C. M. Dahlin, C.D. Blinderman, J. Jacobsen, W.F. Pirl, J.A. Billings, T.J. Lynch, Early
- palliative care for patients with metastatic non-small-cell lung cancer, N. Engl. J. Med. 363 (2010) 733–742.
- [72] N. Levy, Forced to be free? Increasing patient autonomy by constraining it, J. Med. Ethics 40 (2014) 293–300.
- [73] L. Rosenbaum, Invisible risks, emotional choices—mammography and medical decision making, N. Engl. J. Med. 371 (2014) 1549–1552.
- [74] A. Tversky, D. Kahneman, The framing of decisions and the psychology of choice, Science 211 (1981) 453–458.
- [75] T.C. Hoffmann, V.M. Montori, C. Del Mar, The connection between evidence-based medicine and shared decision making, J Am Med Assoc. 312 (2014) 1295–1296.