

ORIGINAL REPORT

## THE POTENTIAL FOR SHARED DECISION-MAKING AND DECISION AIDS IN REHABILITATION MEDICINE

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**Objective:** Shared decision-making and the use of decision aids are increasingly promoted in various healthcare settings. The extent of their current use and potential in rehabilitation medicine is unknown. The aim of the present study was to explore the barriers to and facilitators of shared decision-making and use of decision aids in daily practice, and to explore the perceptions of physical and rehabilitation medicine (PRM) physicians toward them.

**Methods:** A cross-sectional survey of 408 PRM physicians was performed (response rate 31%).

**Results:** PRM physicians expressed the highest levels of comfort with shared decision-making as opposed to paternalistic and informed decision-making. The majority reported that shared decision-making constituted their usual approach. The most important barriers to shared decision-making were cases in which the patient received conflicting recommendations and when the patient had difficulty accepting the disease. Key facilitators were the patient's trust in the PRM physician and the patient being knowledgeable about the disease and about treatment options. PRM physicians' attitudes towards the use of decision aids to inform patients were moderately positive.

**Conclusion:** Shared decision-making appears to have great potential in the rehabilitation setting. Increasing the use of decision aids may contribute to the further implementation of shared decision-making.

**Key words:** decision-making; psychological models; patient participation; patient satisfaction; physician-patient relations; personal autonomy; human.

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### INTRODUCTION

In recent years, the role of the patient in healthcare decision-making has changed. There is a trend towards greater involvement by patients in their personal healthcare management. Patient preferences for disease management are considered increasingly important, and some feel they should influence individual decision-making (1). A greater degree of patient involvement in healthcare decision-making necessitates a change in the interaction between patient and physician. The

traditional paternalistic approach to decision-making assumes that the physician is the expert and the one who actively makes decisions (2). This approach makes few, if any, concessions to patient preferences for the treatment outcome and process. To increase patient involvement, alternative approaches to decision-making have been proposed. The informed decision-making model is the opposite of the paternalistic approach. In the informed decision-making model, the role of the physician is to provide the patient with all relevant information about the disease and treatment options. The “informed” patient is then considered to be capable of making the treatment decision on his or her own (2). This model is criticized because it gives all decision control to the patient and undermines the role of the physician.

In recent years the shared decision-making (SDM) model has been promoted (3–4). SDM consists of the simultaneous participation of the physician and patient in all phases of the decision-making process. Information is exchanged between patient and physician, and the disease and the treatment are deliberated and negotiated. Ideally, agreement is reached about the optimal treatment and treatment is commenced accordingly (2). To enable patients to participate in decision-making, they have to be informed about their disease and its treatment. Information provision is the responsibility of the physician, but it can be supported through the use of decision aids (DAs). A DA is an intervention designed to help patients make specific and deliberative choices among options by providing information on the options and outcomes relevant to a patient's health (5–7). It differs from traditional educational materials because it explicitly describes treatment options, includes quantitative and qualitative information about benefits and risks, tailors information to the individual patient and motivates patients to view the information in light of their own values and preferences (8–9).

Our field of rehabilitation medicine would seem to be an excellent environment for SDM. Adherence to treatment plans, psychological adjustment to disease and working towards patient autonomy are important goals in rehabilitation medicine (3, 10). It has been shown previously that SDM increased satisfaction with the decision-making process (11–13), improved patient adherence to treatment plans (11–12, 14) and resulted in better psychological adjustment to illness (11). One possible drawback of SDM is increased anxiety in patients because it reveals the uncertainties of healthcare decision-making (15–16).

The process of rehabilitation medicine also seems to facilitate SDM. There is a high contact frequency between the physical medicine and rehabilitation (PRM) physician and the patient. Moreover, decision-making in rehabilitation medicine is already shared among different medical disciplines, and formally including the patient as a decision-maker seems to be a relatively small step.

Despite the expected opportunities for SDM in rehabilitation care, only a few studies have empirically examined the value and use of SDM and DAs in rehabilitation medicine. These studies (4, 17–18) indicate that SDM could indeed have beneficial effects on patient autonomy. However, these studies have focused on the patient's perspective on SDM. To our knowledge no previous studies have investigated PRM physicians' perspectives on SDM and DAs in rehabilitation medicine. Therefore, the first aim of this study was to investigate PRM physicians' perceptions of SDM, and the perceived barriers to and facilitators of the implementation of SDM in rehabilitation medicine. The second aim was to explore PRM physicians' perceptions of the usability of DAs to support SDM.

## METHODS

### *Participants and data collection*

A cross-sectional survey of Dutch PRM physicians was undertaken in 2008. PRM physicians were identified through the Dutch Association of PRM Physicians (*Vereniging van Revalidatieartsen*). Only practising PRM physicians were selected. A paper-and-pencil questionnaire was sent to 408 PRM physicians along with a letter inviting them to participate in the study. A prepaid return envelope was enclosed. No incentive for participation was offered. The PRM physicians were asked to return the completed questionnaire within 3 weeks. One reminder was sent after 4 weeks.

### *Questionnaire design*

The questionnaire consisted of 3 parts: the first part collected background variables of the PRM physicians; the second part assessed the PRM physicians' behaviour and attitudes towards decision-making; and the third part focused on the PRM physicians' attitudes towards DAs.

### *Background variables*

The background variables of age, years in practice, average number of patients seen per week and the duration of an average consultation were collected with an open answer format. Information about gender, the average amount of time spent on direct patient care and the primary work setting were collected using a pre-structured answer format. PRM physicians were instructed to consider their primary work setting for the remainder of the questionnaire.

### *Attitude and behaviour towards shared decision-making*

The second part of the questionnaire consisted of a series of questions originally developed by Charles et al. (19) to assess the use of SDM among breast cancer specialists and to explore the perceived barriers to and facilitators of implementing SDM. The original questionnaire was kindly provided by the authors. All questions were translated into Dutch by 3 native speakers (JvT, SD and AP). When there was disagreement, the wording of the question was discussed until agreement was reached. Questions that were not relevant to the rehabilitation population were omitted.

Four approaches to patient–physician interaction were presented in the questionnaire: (i) the physician dominating the interaction (paternalistic approach); (ii) some sharing of information between patient and physician, but with the physician acting as the sole decision maker (“partial sharing” approach); (iii) the patient and physician simultaneously participating in each phase of the decision process (shared approach); and (iv) the physician providing information to the patient while the patient was the sole decision-maker (informed approach). The PRM physicians were asked to indicate which of the 4 examples their usual decision-making approach was most like. Then they were asked to rate their level of comfort with each approach on a 5-point Likert scale (1 = not comfortable to 5 = extremely comfortable). A score of 4 or 5 was re-coded to “a high level of comfort with an approach” and the number and percentage of PRM physicians who indicated a high degree of comfort with an approach are reported in the results.

To study the perceived barriers to and facilitators of SDM in rehabilitation medicine, respondents were asked to indicate the extent to which they perceived each of 19 factors to be a barrier to the decision-making process and each of 11 factors as facilitators of the decision-making process on a 4-point Likert scale (1 = never to 4 = always). In accordance with Charles et al. (19), responses 1 and 2 were collapsed into “no, not a facilitator (or barrier)” and responses 3 and 4 were collapsed into “yes, a facilitator (or barrier)”. Free text fields were used to give PRM physicians the opportunity to state their own opinions and thoughts with regard to decision-making.

Additional questions focused on perceived patient attitudes towards SDM (4 items). These questions were based on an item list developed by Holmes-Rovner et al. (9), which is further described in the next paragraph.

### *Attitude towards decision aids*

The third part of the questionnaire was focused on the PRM physicians' perceptions of DAs. An example of a DA was presented to introduce the concept to the PRM physicians. The example consisted of 4 screenshots from an online DA intended for patients after stroke. The URL of the DA was provided to enable the PRM physicians to view the whole DA. It was not verified whether the PRM physicians did so.

A series of statements was posed as to the extent to which physicians consider DAs useful in the clinical setting. The statements were based on an article by Holmes-Rovner et al. (9). Again, the questions were translated into Dutch by 3 native speakers, after which the wording of the questions was discussed until agreement was reached (JvT, SD, AP). The statements focused on whether a DA should be used (2 items), the perceived administrative impact of DAs (3 items) and the perceived effect of DAs on SDM (3 items). PRM physician agreement with the statements was rated on a 5-point Likert scale (1 = strongly disagree to 5 = strongly agree). Responses 1 and 2 were collapsed into “disagree” and responses 4 and 5 were collapsed into “agree”. Free text fields were added to give PRM physicians the opportunity to add their own opinion with regard to the potential of DAs.

### *Statistical analysis*

The data were analysed descriptively using the means and standard deviations and by using frequency analysis. Spearman correlations were computed to test whether PRM physicians' work characteristics (time spent on direct patient care, number of patients seen, duration of the average consultation) were correlated.

To test whether the PRM physicians' attitudes towards the decision-making approaches and their usual approach to decision-making are related to individual characteristics of the PRM physicians (i.e. gender, age and work experience) or to their work setting (i.e. clinical setting, workload and diagnostic group), correlations were calculated. A 2-tailed *p*-value of 0.05 was considered significant.

SPSS statistical software package version 15.0 was used for the statistical analyses.

Table I. Physical and rehabilitation medicine physicians' demographic and work characteristics (n = 126)

Characteristics	n (%)
Gender	
Female	56 (44)
Male	70 (56)
Age, years	
31–40	47 (37)
41–50	41 (33)
> 50	38 (30)
Years in practice	
≤ 5	41 (33)
6–10	25 (20)
11–15	17 (14)
16–20	18 (14)
> 20	25 (20)
Clinical work setting	
Hospital	59 (53)
Rehabilitation centre	52 (47)
Time spent on patient care	
≤ 8 h per week	2 (2)
8–16 h per week	22 (18)
16–24 h per week	51 (41)
> 24 h per week	50 (40)
Number of patients	
≤ 25 per week	45 (38)
26–50 per week	57 (48)
51–75 per week	14 (12)
> 75 per week	3 (2)
Duration of average consultation	
≤ 15 min	19 (17)
16–30 min	84 (73)
31–45 min	12 (10)

Percentages are based on valid cases only.

## RESULTS

### Response rate and work characteristics

Of the 408 eligible PRM physicians, 126 (31%) completed and returned the questionnaire. The majority of respondents were male, age range 31–40 years, and had been working as PRM physicians for less than 5 years. Over 80% of PRM physicians spent more than 20 h a week on direct patient care, and approximately 50% had between 26 and 50 unique patient contacts each week (Table I). As might be expected, PRM physicians who had more unique patient contacts in a week spent more time on direct patient care ( $r = 0.434$ ;  $p = 0.001$ ) and the duration of their average consultation was significantly lower ( $r = -0.264$ ;  $p = 0.005$ ). The PRM physicians ( $n = 126$ ) treated amputees (68%), burn victims (4%), chronic pain (85%),

Table II. Physical and rehabilitation medicine physicians' self-reported usual decision-making approach and level of comfort with decision-making approach (n = 126)

Decision-making model	Usual approach, n (%)	High comfort level, n (%)
Paternalistic approach	3 (3)	31 (25)
Some sharing	31 (27)	74 (60)
Shared approach	58 (50)	99 (81)
Informed approach	19 (16)	60 (48)
Missing/other	5 (4)	

Percentages are based on valid cases only.

spinal cord injury (43%), heart disease (18%), neuromuscular diseases (80%), traumata (65%), traumatic brain injury (73%) and patients after stroke (95%). PRM physicians who cited a speciality ( $n = 91$ ) stated that their main patient group was patients with chronic pain (29%), stroke (28%), neuromuscular disease (7%), traumatic brain injury (4%), amputation (3%), spinal cord injury (3%), traumata (2%), and "other disease" (24%, most frequently children). Thirty-five PRM physicians did not cite a specialty.

### Attitude and behaviour towards shared decision-making

Eighty-one percent of PRM physicians reported a high level of comfort with the SDM approach. This percentage was higher than the results for any of the other approaches to decision-making. Fifty percent of PRM physicians indicated that the SDM approach was their usual approach to decision-making. Only 3% of PRM physicians adopted a paternalistic approach, where no patient participation in decision-making takes place (Table II).

The majority of the respondents (60%) indicated that they initiate a discussion about the extent to which the patient wants to participate in the decision-making process with their patients on a regular basis. Only 28% indicated that their patients initiate a discussion about their desired degree of participation in the decision-making process on a regular basis. This indicates that, according to the PRM physicians, the initiative for SDM more often lies with the PRM physicians.

The majority (80%) of the respondents also stated that they inform their patients when more treatment options are available. In such cases, most PRM physicians (66%) recommended further treatment (data not presented).

PRM physicians' perceptions of their patients' desire to participate in treatment decision-making are moderately positive (Table III). More than half of the PRM physicians agreed that

Table III. Physical and rehabilitation medicine physicians' perceptions of patient attitudes towards shared decision-making

Patient attitude towards shared decision-making	n	Disagree, n (%)	Agree, n (%)
Knowing risks and benefits, most patients want to decide how acceptable treatment is to them	123	17 (14)	65 (53)
Patients usually want to be an equal partner with physicians in making important treatment decisions	124	50 (40)	26 (21)
Majority of patients do not wish to be involved in decision-making about their treatment	125	79 (63)	11 (9)
Most patients prefer the doctor to take responsibility for their medical problems	125	26 (21)	23 (19)

Percentages based on valid cases only.

Table IV. Barriers to shared decision making in rehabilitation medicine (n = 126)

Barriers to shared decision-making	n	Yes, a barrier, n (%)
The patient has received conflicting recommendations from specialists	124	88 (71)
The patient has difficulty accepting his/her disease	122	83 (68)
The patient has misconceptions about the disease or treatment	122	75 (62)
The patient's family overrides the decision-making process	121	62 (51)
The patient requests a treatment not known to be beneficial	123	60 (49)
The patient does not understand the information I have provided	124	57 (46)
The patient is too anxious to be able to listen to what I have to say	122	54 (44)
There are cultural differences between the patient and me	123	52 (42)
The patient is indecisive	124	51 (41)
I have insufficient time to spend with the patient	124	51 (41)
The patient does not want to participate in treatment decision-making	121	47 (38)
The patient comes expecting treatment rather than consultation	123	47 (39)
The patient brings too much information to discuss	122	42 (34)
The patient refuses a treatment that may benefit him/her	122	41 (34)
I have insufficient information to make a decision about treatment	124	41 (33)
The patient has other health problems	122	39 (32)
The patient wants to make a decision before receiving information	122	36 (30)
The patient wants to participate too much in deciding on his/her treatment	123	23 (19)
I experience difficulty knowing how to frame the treatment options	121	11 (9)

Percentages are based on valid cases only.

most patients with adequate knowledge of risks and benefits would want to participate in decision-making. Although 40% of PRM physicians felt that patients do not want to be an equal partner in decision-making, the results of this study indicate that, according to the PRM physicians, only a minority of their patients did not want a role in or responsibility for treatment decision-making.

Approximately half of the PRM physicians who participated in the study used the free text fields to add one or more comments. Most comments indicated that there is no "usual" approach to decision-making, but that the approach to decision-making is dependent on the disease and the specific capabilities of the patient. Specifically, cognitively impaired patients, children and chronic pain patients with a behavioural component were thought to be limited in their ability to participate in decision-making. Additionally, the patient's recovery phase and the type of decision that has to be made influence the approach to decision-making, according to the PRM physicians. Some PRM physicians also felt that despite their desire to involve a patient in decision-making, some patients do not want to be

involved and instead ask their PRM physician, "What would you do?"

The 3 most frequently mentioned barriers to SDM were the patient receiving conflicting recommendations from different specialists, patients' difficulty accepting disease and patients' misconceptions about disease or treatment (Table IV). Of note, the majority of PRM physicians did not feel that their own knowledge of the process of SDM and decision-framing capacity were barriers to SDM. The time barrier, which is frequently mentioned in the literature, is experienced by approximately 40% of PRM physicians in our study sample.

Almost all PRM physicians considered the patient's trust in the PRM physician to be a facilitator of SDM. All factors related to the patient being ready for decision-making, being informed and having support were frequently mentioned (by > 80% of PRM physicians) as facilitators of SDM (Table V). Contact with fellow patients or support groups and with other people (doctors or friends) working in the healthcare system, were regarded as less important.

Table V. Facilitators of shared decision making in rehabilitation medicine

Facilitators of shared decision-making	n	Yes, a facilitator, n (%)
The patient trusts me	125	123 (98)
The patient has emotional support from family or others	125	119 (95)
The patient is prepared (knowledgeable about the disease and treatment) prior to the consultation	125	117 (94)
The patient has someone with them at the consultation	123	114 (93)
The patient wants to participate in making the treatment decision	125	114 (91)
The patient is emotionally ready for decision-making	125	102 (82)
Written information has been provided to the patient	125	102 (82)
The patient talks to someone else with the same condition	122	90 (74)
The patient has contact with a support group	124	73 (59)
The patient seeks a second medical opinion	123	59 (48)
The patient has friends who work in the healthcare system	124	47 (38)

Percentages are based on valid cases only.

A few PRM physicians expressed some additional considerations (in the free text fields) that could be interpreted as barriers to SDM. Some PRM physicians expressed the thought that no decision-making takes place once a patient is admitted to a rehabilitation ward. One other PRM physician commented that the lack of clearly defined treatment alternatives in rehabilitation medicine, as opposed to oncology or orthopaedic surgery, makes SDM difficult.

#### *Attitudes towards decision aids*

The PRM physicians in our sample have fairly positive attitudes towards the use of DAs. A small majority of PRM physicians felt that patients would be better informed after contact with a DA and that eligible patients should be referred to a DA (Table VI). The majority of PRM physicians felt that DAs would have a positive effect on SDM, with patients being better informed and asking more questions. Overall, PRM physicians did not feel that DAs would reduce the amount of time spent on educating patients or improve the quality of healthcare (by reducing the incidence of malpractice and/or patient need for a second opinion).

#### *Influence of PRM physicians characteristics on decision-making behaviour*

There were 2 major categories of PRM physicians in our sample: PRM physicians who mainly treat patients with chronic pain (chronic pain), and PRM physicians who mainly treat patients after stroke. More patient involvement was reported by PRM physicians working with chronic pain patients compared with PRM physicians working with patients after stroke. More than 40% of PRM physicians working with chronic pain patients indicated that the shared approach is their usual approach to decision-making, while more than 40% of PRM physicians working with patients after stroke prefer the partial sharing approach (data not presented). No significant correlations were found between PRM physicians' age or years in practice and their attitudes toward the 4 decision-making models and PRM physicians' usual approach to decision-making. Male PRM physicians ( $r=0.215$ ;  $p=0.017$ ) and PRM physicians who treat greater numbers of patients ( $r=0.289$ ;  $p=0.001$ ) during the week are more likely to be comfortable with the informed decision-making approach.

## DISCUSSION

The aim of this study was to investigate PRM physicians' perceptions of SDM and DAs. The high levels of comfort with the SDM approach indicated a positive attitude on the part of PRM physicians towards including patient preferences in the decision-making process. The majority of PRM physicians reported that the SDM approach was their usual approach to decision-making, and only a few PRM physicians felt that they employed a paternalistic approach. It should be noted that, in this study, we measured the PRM physicians' perceptions of their current practice, not actual SDM. Therefore, the value of this study is in building a hypothesis with regard to the potential for SDM and DAs in rehabilitation medicine. Future research into the actual practice of SDM will be needed. Yet, PRM physicians' positive perceptions of sharing decision control, found in the present study, seem to be supported by previous studies which indicated that patients in rehabilitation medicine experienced a strong sense of involvement in their rehabilitation process (4, 18, 20).

The most important barrier to SDM that was identified in this study was "conflicting recommendations from different health professionals". It is likely that the multi-disciplinary nature of rehabilitation medicine will result in a higher frequency of conflicting recommendations compared with situations in which SDM has traditionally been studied (i.e. situations in which only one patient and one physician are involved). When more medical disciplines are involved in treatment differences in training or focus are likely to influence the preferred focus and execution of treatment (21). Different recommendations from a PRM physician and, for instance, a physical or occupational therapist, highlight the value-sensitive nature of decision-making in rehabilitation medicine, but they can be confusing to the patient.

PRM physicians did report that their approach to decision-making was strongly related to the willingness and ability of the patient to participate. The respondents, who were on average positive, cautioned that the ability of a patient to participate in decision-making is influenced by their age, disease and time elapsed since injury. For instance, patients after stroke and children were mentioned as patient groups for whom the ability to participate in shared decisions might be limited. The

Table VI. *Physical and rehabilitation medicine physicians' attitudes towards the use of decision aids in rehabilitation medicine*

Attitude towards DAs	<i>n</i>	Disagree, <i>n</i> (%)	Agree, <i>n</i> (%)
<i>Need for and effect of DAs (DA)</i>			
Patients should see DA before treatment decision is made	125	35 (38)	37 (30)
Patients using a DA will be better informed	125	11 (9)	70 (56)
All eligible patients should be referred to a DA	124	20 (16)	66 (53)
A DA may cause some patients to make the wrong choice	125	41 (33)	46 (37)
<i>Impact of DAs on shared decision-making</i>			
DA will cause patients to be more involved in decision-making	124	14 (11)	79 (64)
DA will cause patients to ask more questions than they would otherwise have asked	124	10 (8)	77 (62)
<i>Administrative impact of DAs</i>			
With a DA I will be able to reduce time spent educating patients about treatment	124	50 (40)	31 (25)
A DA will reduce the risk of malpractice	124	53 (43)	21 (17)
A DA will eliminate the need for third-party involvement, such as second opinion	122	75 (61)	23 (19)

Percentages based on valid cases only.

same problems with ability to participate have been previously identified in mental health (22). Earlier studies in rehabilitation medicine indicate that patients are in a state of transition with regard to autonomy during the rehabilitation process (3–4, 20). This indicates that decision sharing in rehabilitation medicine is not a static concept. As in mental health, PRM physicians should take into account both the willingness and the ability of patients to share in making decisions (22). Future studies on SDM in rehabilitation medicine should be disease-specific in order to take into account the cognitive and physical impairments of the mixed diseases in rehabilitation medicine.

Some PRM physicians expressed the, rather surprising, idea that no decision-making takes place once a patient is admitted to a rehabilitation unit. Obviously, this cannot be true or there would be no role for the PRM physician in chronic rehabilitation care. We speculate that actual decisions and the time at which they are made may be less recognizable to PRM physicians compared with the process involved in the cases that are the traditional focus of SDM, concerning life-threatening disorders and 2 different treatment options. Rather than a single decision about treatment, which is subsequently followed through, decision-making in rehabilitation medicine is an ongoing process of decisions. Because of the chronic nature of the diseases involved, decisions can be postponed or reconsidered without irreversible consequences to the patient. For the model of SDM to fit the situation of rehabilitation care, it requires tailoring, as was previously done for chronic diseases such as diabetes and kidney disease (23–25).

This study indicates that PRM physicians hold a modestly positive attitude towards the ability of DAs to inform patients. Most PRM physicians felt that the use of DAs would not decrease the time they spend on educating patients. However, in agreement with our expectations, time constraints were not perceived of as an important barrier to the implementation of SDM (26).

Some limitations of this study should be taken into consideration. First, the response rate was low compared with the study by Charles et al. (19). However, the distribution of PRM physicians with regard to age, experience and diagnostic mix indicates that a wide range of Dutch PRM physicians was reached. It must be taken into account that PRM physicians with a more positive attitude towards SDM might have been more inclined to return the questionnaire. Also, given the increased amount of attention to SDM in the literature and in clinical practice, social desirability might have influenced the results of this study. These factors may have resulted in an overestimation of the use and positive attitude towards SDM. With regard to the potential of DAs, it must be taken into account that the use of true DAs is limited in rehabilitation medicine. It is likely that PRM physicians' experience with DAs is limited and that their ability to accurately estimate the effectiveness of DAs is likewise limited. Finally, the fact that this study relied on self-reported measures must be taken into account. The use of self-reported measures has previously resulted in an overestimation of the actual degree of information provision and SDM compared with analyses of audio- and video-tapes (27).

In future research a tailored model of SDM in chronic rehabilitation care should be developed. Further research should also be more disease-specific by focusing on the characteristics of the patient group and on how these variables influence the use and perceived use of SDM and DAs. In addition, more research into the patient perspective on SDM is necessary.

In conclusion, the most important finding of this study is that PRM physicians report high levels of comfort with the SDM approach. These results suggest that PRM physicians are willing to share decision control with the patient. Whether SDM is actually practiced is influenced by the characteristics of the patient group and the clinical situation, mostly noticeably by the cognitive abilities of the patient. Future research should focus more particularly on the barriers that are specific to rehabilitation medicine and on how these can be overcome. The potential of DAs should be further investigated in actual clinical decision-making.

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