On how to define and measure SDM

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Editorial

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In their paper in this issue of PEC, Callon et al. introduce an expanded framework to define and measure shared decision making (SDM) between clinicians and parents making decisions about elective otolaryngology surgery for their children [1]. They aim to allow for a more comprehensive understanding and analysis of SDM. Their endeavor to develop the coding scheme was based on their felt need to supplement the more theoretical 'top-down' approach through which existing coding schemes often were developed with a descriptive 'bottom-up' approach, based on observation of patient-clinician dialogue. The problem they indicate with existing coding schemes is that some of the required elements are rarely performed in practice. Why this is a problem is not fully clear to us, but it seems that they dislike clinicians being penalized for not performing SDM to an acceptable standard. With their bottom-up approach, they wish to expand the range of communication behaviors related to SDM by including behaviors that clinicians display more commonly. Their investigation raises a number of questions that we deemed worth further thought.

To our surprise, Callon et al. do not start by providing a definition of SDM but by indicating how they compiled their coding system, consisting of clinician and patient behaviors. Their top-down approach was to select behaviors from the OPTION-12, MAPPIN'SDM, and Braddock et al.'s model. The selection of these three coding schemes seems somewhat arbitrary. The behaviors of the MAPPIN'SDM were largely based on the OPTION12, including those rephrased to assess patient behavior [2], and few authors have applied the instrument to date. Braddock developed a scheme that was used by others to assess SDM [3] but SDM was not the underlying construct that it aimed to measure [4]. One may argue that the latter is true also for the OPTION12 [5], but it has been used so extensively to code SDM that we may concede that there is agreement that it captures relevant clinician SDM behaviors. Noteworthy is that Callon et al included *any* clinician behavior, but for patient, in casu parent, behavior they limited their selection to those that made most sense to them. This 'sense' could be, e.g., that their group felt that a role assigned to the patient was unrealistic.

Their bottom-up approach consisted of audiotaping patient-parent-clinician encounters, and selecting those behaviors that were 'relevant to decision making'. In this way they identified three domains not present in the three selected coding schemes: emotional environment of the encounter, clinician use of clear language, and recommendations. Partnership between clinicians and patients [6-8], the use of clear language [9-11] and checking patient understanding [8,9,12,13], and the provision of recommendations [9-11,13-16], are part of existing SDM definitions. Yet, based on a bottom-up approach it cannot be determined whether these domains are *SDM* domains. This is the first problem we identify with the authors' bottom-up approach. Observed behavior may be relevant to any model of decision making, or may even be considered general communication skills, and not exclusive for SDM. Measuring such behavior will not inform the extent to which SDM occurred if there is no external criterion for, nor definition of, the occurrence of SDM. Secondly, behavior may be specific to SDM but not necessarily part of the process itself, and rather a facilitator or

condition for the occurrence of SDM. For example, regarding emotional support, we know that distress may (temporarily) hamper patient's ability to absorb and understand information [17-19], weigh information [17], and voice questions [19], and adequate clinician communication can help relieve concerns [20]. Paying attention to the emotional environment of the encounter thus seems to impact aspects that are highly relevant to SDM. Joseph-Williams and colleagues [21] thus identified e.g., listening to patient concerns and having positive interpersonal skills as patient-reported *facilitators* for SDM. Third, observation of behavior necessarily happens from a particular theory or preconceived idea of what is relevant to attend to. The authors do not make explicit what their definition is of SDM. They relate selection of relevant behaviors to the broader question of whether the focus should be on a *descriptive* or *normative* approach. This question may be problematic, as we do not have a theory of SDM that can guide us in what SDM is, from a normative point of view. Also, we cannot describe SDM simply by observing consultations, without any criterion or definition as we have argued above. There exist at least 22 different definitions of SDM that aim to describe the process [22]. A specific model, or an integration of the models can be used to determine what SDM should entail, and a description of how decision processes unfold can then be weighed against this model.

The inclusion of the clinician's recommendation is part of several definitions of SDM. The authors describe four types of recommendations, and conclude that recommendations are possibly only to be seen as negative in a situation of complete equipoise. And even in such a situation, it may be positive if the patient asks for it. But what is an 'SDM-proof' recommendation? Recommendations, especially when posited as 'authorized decisions' such as "The standard of treatment is surgery" can be considered as implicit persuasive utterances [23] and may not, contrary to the authors' judgment, be qualified as soft recommendations in preference-sensitive decision situations. Moreover, evidence suggests that recommendations can steer patients towards options that patients do not prefer [24]. The key question is how the recommendation should be formulated and, perhaps more importantly, at what point in the decision process it should be provided [25]. We suggest that the crucial distinction between a fitting provider recommendation in an SDM setting versus one in other, clearly effective decision situations, is whether or not patient goals or preferences were incorporated into the recommendation. Patients consider receiving a recommendation as part of SDM [15,26] and *if* the recommendation incorporates the patient's goals or preferences, it is clearly part of the SDM process [27]. Thus, even upon explicit patient request for a recommendation, clinicians should withhold it until "preference talk" has occurred.

Finally, SDM cannot be assessed from one perspective only and, as the authors note, an observer-based instrument is inherently limited. SDM can hardly be considered as some object out there, and evidence has shown how the perspective from which it is being evaluated matters [2,28,29]. SDM is displayed in communicative behaviour and is perceived in participants' minds. E.g., a patient can report to have received full information, without being told all the relevant information based on observation [30]. A provider can also recount to have heard a patient's preferences, while the patient reports to have withheld relevant concerns. Moreover, limiting assessments of SDM to observation requires the selection of specific occasions to observe. This will necessarily restrict the view on SDM in ways that

may leave out relevant parts of the process, especially those that occur outside of medical consultations [31], and involve patients' consultation with significant others [6,32].

In conclusion, Callon et al. offer a detailed coding scheme that aims to capture goals key to SDM. Their selection of goals and underlying behaviors may warrant additional testing, to determine face and content validity of the instrument. In addition, patient outcomes, as the authors suggest, should not be used for validation of an SDM instrument, since results regarding possible relations may be inconclusive [33,34]. The authors rightly advocate the investigation of a broader view on SDM, allowing the incorporation of elements that may have been excluded in many existing schemes. We strongly recommend to involve the perspective of clinician, patients, and others involved to clearly delineate what is SDM and what should be considered the broader context: patient-centred communication.

References

[1] W. B. Callon, M.C. Beach, A.R. Links, C. Wasserman, E.F. Boss, An expanded framework to define and measure shared decision-making in dialogue: A 'top-down' and 'bottom-up' approach, Patient Educ Couns (2018).

[2] J. Kasper, F. Hoffmann, C. Heesen, S. Kopke, F. Geiger, MAPPIN'SDM--the multifocal approach to sharing in shared decision making, PLoS. One 7 (2012) e34849.

[3] F. R. Gärtner, H. Bomhof-Roordink, I. P. Smith, I. Scholl, A. M. Stiggelbout, A. H. Pieterse, The quality of instruments to assess the process of shared decision making: A systematic review, PLoS One 13 (2018) e0191747.

[4] 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.

[5] 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.

[6] B. A. Lown, W. D. Clark, J. L. Hanson, Mutual influence in shared decision making: a collaborative study of patients and physicians, Health Expect 12 (2009) 160-174.

[7] V. M. Montori, A. Gafni, C. Charles, A shared treatment decision-making approach between patients with chronic conditions and their clinicians: the case of diabetes, Health Expect 9 (2006) 25-36.

[8] A. Towle, W. Godolphin, Framework for teaching and learning informed shared decision making, BMJ 319 (1999) 766-771.

[9] 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.

[10] K. Grim, D. Rosenberg, P. Svedberg, U. K. Schon, Shared decision-making in mental health care-A user perspective on decisional needs in community-based services, Int J Qual Stud Health Well-being 11 (2016) 30563.

[11] M. E. Peek, M. T. Quinn, R. Gorawara-Bhat, A. Odoms-Young, S. C. Wilson, M. H. Chin, How is shared decision-making defined among African-Americans with diabetes?, Patient Educ Couns 72 (2008) 450-458.

[12] G. Elwyn, 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 27 (2012) 1361-1367.

[13] G. Makoul, M. L. Clayman, An integrative model of shared decision making in medical encounters, Patient Educ Couns 60 (2006) 301-312.

[14] K. Karkazis, A. Tamar-Mattis, A. A. Kon, Genital surgery for disorders of sex development: implementing a shared decision-making approach, J Pediatr Endocrinol Metab 23 (2010) 789-805.
[15] L. A. Shay, J. E. Lafata, Understanding patient perceptions of shared decision making, Patient Educ Couns 96 (2014) 295-301.
[16] R. J. Volk, N. K. Shokar, V. B. Leal, R. J. Bulik, S. K. Linder, P. D. Mullen, R. M. Wexler, G. S. Shokar, Development and pilot testing of an online case-based approach to shared decision making skills training for clinicians, BMC Med Inform Decis Mak 14 (2014) 95.
[17] L. J. Caldon, K. A. Collins, M. W. Reed, S. Sivell, J. Austoker, A. M. Clements, J. Patnick, G. Elwyn, Clinicians' concerns about decision support interventions for patients facing breast cancer surgery options: understanding the challenge of implementing shared decision-making, Health Expect 14 (2011) 133-146.
[18] E. Peters, M. A. Diefenbach, T. M. Hess, D. Vastfjall, Age differences in dual information-processing modes: implications for cancer decision making, Cancer 113 (2008) 3556-3567.
[19] C. D. Prouty, K. M. Mazor, S. M. Greene, D. W. Roblin, C. L. Firneno, C. A. Lemay, B. E. Robinson, T. H. Gallagher, Providers' perceptions of communication breakdowns in cancer care, J Gen. Intern. Med 29 (2014) 1122-1130.
[20] K. Brandes, A. J. Linn, E. G. Smit, J. C. M. van Weert, Patients' reports of barriers to expressing concerns during cancer consultations, Patient Education and Counseling 98 (2015) 317-322.
[21] N. Joseph-Williams, G. Elwyn, A. Edwards, Knowledge is not power for patients: a systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making, Patient Educ Couns 94 (2014) 291-309.
[22] H. Bomhof-Roordink, F.R. Gärtner, A.M. Stiggelbout, A.H. Pieterse, Conceptual Models of Shared Decision Making: A Systematic Review of the Literature, Abstract presented at the European meeting of the Society of Medical Decision Making, Leiden, The Netherlands, 2018.
[23] E. G. Engelhardt, A. H. Pieterse, A. van der Hout, H. J. de Haes, J. R. Kroep, P. Quarles van Ufford-Mannesse, J. E. Portielje, E. M. Smets, A. M. Stiggelbout, Use of implicit persuasion in decision making about adjuvant cancer treatment: A potential barrier to shared decision making, Eur J Cancer 66 (2016) 55-66.
[24] R. Mendel, E. Traut-Mattausch, D. Frey, M. Buhner, A. Berthele, W. Kissling, J. Hamann, Do physicians' recommendations pull patients away from their preferred treatment options?, Health Expect 15 (2012) 23-31.
[25] J. Hamann, W. Kissling, R. Mendel, Does it matter whether physicians' recommendations are given early or late in the decision-making process? An experimental study among patients with schizophrenia, BMJ Open 6 (2016) e011282.
[26] N. P. Tamirisa, J. S. Goodwin, A. Kandalam, S. K. Linder, S. Weller, S. Turrubiate, C. Silva, T. S. Riall, Patient and physician views of shared decision making in cancer, Health Expect 20 (2017) 1248-1253.
[27] A. M. Stiggelbout, A. H. Pieterse, J. C. de Haes, Shared decision making: Concepts, evidence, and practice, Patient Educ Couns 98 (2015) 1172-1179.
[28] L. Kriston, M. Härter, I. Scholl, A latent variable framework for modeling dyadic measures in research on shared decision-making, Z Evid Fortbild Qual Gesundhwes 106 (2012) 253-263.
[29] I. Scholl, L. Kriston, J. Dirmaier, M. Härter, Comparing the nine-item Shared Decision-Making Questionnaire to the OPTION Scale - an attempt to establish convergent validity, Health Expect 18 (2015) 137-150.

[30] V. Crispin, C. Bugge, K. Stoddart, Sufficiency and relevance of information for inpatients in general ward settings: A qualitative exploration of information exchange between patients and nurses, Int J Nurs Stud 75 (2017) 112-122.
[31] M. L. Clayman, P. Gulbrandsen, M. A. Morris, A patient in the clinic; a person in the world. Why shared decision making needs to center on the person rather than the medical encounter, Patient Educ Couns (2016) 600-604.
[32] H. Bomhof-Roordink, N. van Duijn-Bakker, M. Baas-Thijssen, A. Stiggelbout, A. Pieterse, What is shared decision-making in oncology? A patients', healthcare professionals', general population's and experts' perspective, Abstract presented at the International Shared Decision Making conference, Lyon, France, 2017.
[33] M. S. Kashaf, E. McGill, Does Shared Decision Making in Cancer Treatment Improve Quality of Life? A Systematic Literature Review, Med Decis Making 35 (2015) 1037-1048.
[34] 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.

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