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Measuring shared decision making in oncology: an informed approach

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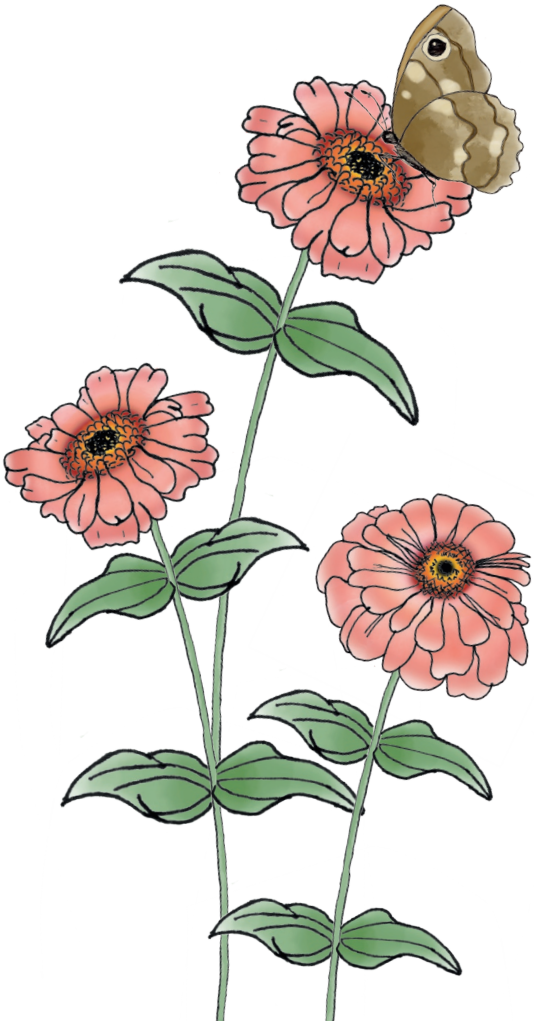

GENERAL INTRODUCTION

Shared decision making (SDM) between patient and healthcare professional about treatment options is becoming 'the new normal' in the Netherlands, envisioned Bruno Bruins, the former Dutch minister of Health in 2019.[1] The Dutch Federation of Medical Specialists considers that SDM should become a habit[2] and, consequently, it may become the new normal. 'The new normal' has gained a completely different meaning in the Netherlands since 2020. It refers to the behaviours asked from each individual to slow the spread of COVID-19.[3] For example, here and elsewhere people have been asked to avoid physical contact and to wash their hands frequently.[4, 5] The recommended behaviours have repeatedly been communicated by the government and are quite easy in themselves, but still adherence has been low. Evidently, commitment to new behaviours is not easy, even for simple behaviours. In contrast, SDM between patient and healthcare professional involves two or more individuals who need to commit to complex behaviours during and outside the clinical consultation. Communication about these behaviour changes by healthcare professional organisations, among others is challenging, and they may not easily become routine for patients and healthcare professionals.

In 1972, Veatch described the contractual model in which there is true sharing of ethical authority and responsibility between patient and physician, next to sharing of decision making. Ten years later, ethically valid informed consent was stated to involve a process of SDM.[6] In the 1990's several journals published papers on SDM,[7-9] and Charles and colleagues presented the first SDM model in 1997 (see Box 1).[10] The BMJ embraced patient partnership with a contribution by Charles and colleagues[11] and by a illustrating it as a tangoing couple on their cover in 1999, upon Charles et al. revisiting their SDM model.[12] In 2006, Makoul & Clayman identified 31 separate concepts used to explicate SDM, from 161 different definitions.[13] A year later, Moumjid et al. concluded that while clear SDM definitions were available, they were poorly cited and that the term SDM was being used inconsistently.[14] Over the following years, the number of publications on SDM increased rapidly.[15]

In 2011 the Salzburg statement called upon patients and healthcare professionals 'to work together to be coproducers of health', with specific tasks for each of them.[16] To date, a range of implementation activities have been undertaken to support SDM, such as: training of healthcare professionals,[17, 18] development of pocket cards for healthcare professionals,[19] and development of patient decision aids.[20, 21] Dutch national campaigns have been launched ('3 goede vragen',[22, 23] 'consultkaart',[24] 'begin een goed gesprek'[25]) to create awareness about SDM, informed by e.g., the AskShareKnow,[26, 27] the Ask 3 questions campaigns,[28] and Option Grids.[29] SDM has even been established by Dutch law; the Dutch Medical Treatment Agreement Act (Wet op de geneeskundige behandelovereenkomst (WGBO)) which regulates the rights and obligations of patients, was adapted recently (January 1, 2020) and now includes reference to SDM.[30]

Box 1. First SDM model by Charles et al.[10, 12]

1. At a minimum, both the physician and patient are involved in the treatment decision-making process.
2. Both the physician and patient share information with each other.
3. Both the physician and the patient take steps to participate in the decision-making process by expressing treatment preferences.
4. A treatment decision is made, and both the physician and patient agree on the treatment to implement.

SDM measurement challenges

While many SDM implementation activities have been launched, measurement difficulties remain.[31-33] In 2011, Scholl et al. identified 28 SDM measurement instruments from the literature and concluded that further psychometric testing was needed, since validity had often not been sufficiently investigated.[34] Moreover, these and more recent measurement instruments only assess healthcare professionals behaviour, or include patient and healthcare professional behaviour in one item. This makes it impossible to assess the patients' role, while their responsibilities have been clearly emphasized since the first SDM models.[10, 12] Measurement of behaviours outside consultations is also lacking, while SDM extends to the world outside the consultation room.[35]

In previous research, patients and healthcare professionals have been involved in the development of SDM measurement instruments to a limited extent only, even though this is recommended.[36] This lack of involvement may partly explain poor correlations between SDM assessments from different viewpoints,[33, 37-40] including an independent observer (e.g., OPTION-5[41]), the patient (e.g., SDM-Q-9,[42]), or the healthcare professional (e.g., SDM-Q-Doc[43]). Patient and healthcare professional involvement will likely improve the content validity of the measurement instruments and for questionnaires, their feasibility and acceptability.

Last but not least, for most existing measurement instruments, the developers apparently have assumed a reflective model, as they assessed factor structure and/or internal consistency. They have thereby neglected the formative nature of the SDM construct. That is, SDM in itself may not be something already present, in contrast to e.g., intelligence.[44, 45] SDM is formed by the behaviours of patients and healthcare professionals, both during and outside consultations. What these behaviours entail, may vary per context. Together the items of a measurement instrument form the construct, while for e.g., intelligence, the items reflect the construct. A consequence of assuming a formative measurement model is that another approach is needed to inform item selection and to determine the validity of a measurement instrument.

Aim and outline

We aimed to develop and validate questionnaires to assess the SDM process in oncology from both the patient and the physician viewpoint. We chose the participant perspective and decided to develop questionnaires instead of a coding scheme to be completed by an independent observer, since questionnaires are far more easy to use in research. To guide our development and validation process, we used the original COnsensus-based

Standards for the selection of health Measurement INstruments (COSMIN) checklist[46, 47] and wrote two reviews: one on published SDM measurement instruments and one on published SDM models. Next, we used several consecutive studies to develop, test, and validate the questionnaires. We chose to develop the questionnaires specifically for oncology, since cancer patients often face preference-sensitive decisions,[48] a decision type for which SDM is considered to be the appropriate approach.[49] Cancer patients' treatment preferences vary[50, 51] and often differ from physicians' treatment preferences.[52, 53] Survival, for example, may be weighed differently by patients and physicians.[52] To ensure that treatment is in line with individual patients' preferences, cancer patients' involvement in decision making is of utmost importance. Fortunately, most cancer patients prefer an active or collaborative role in treatment decision making.[54-56]

In chapter 2, we present an overview of existing SDM measurement instruments and an assessment of the level of evidence for 10 measurement properties. This assessment was informed by the methodological quality of the respective validation study or studies, and by the psychometric quality of the measurement properties. In chapter 3, we present an overview of models defining SDM between a patient and a healthcare professional, the components making up the models, who is seen as responsible for the occurrence of the SDM components, the inclusion of the components over time, and we present a frequency map of SDM components per healthcare setting. In chapter 4, views of stakeholders are integrated into a model of SDM in oncology. Chapter 5 describes the development and first testing of the iSHAREpatient and iSHAREphysician. These questionnaires aim to measure SDM in oncology, from the viewpoint of the patient and of the physician, respectively. In chapter 6 we demonstrate construct validity of the iSHAREpatient and iSHAREphysician, test-retest agreement of the iSHAREpatient, and agreement between scores on the iSHAREpatient and iSHAREphysician. In chapter 7 the main findings are summarized and discussed, including strengths and limitations, practice implications, suggestions for future research and concluding remarks.

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