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To thrive or just survive

Wieringa, T.H.

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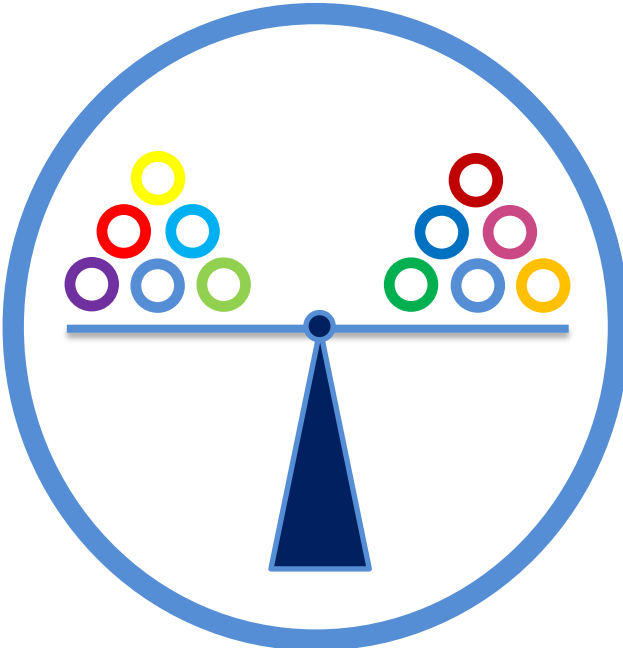
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Summary



Older persons with type 2 diabetes commonly live with a variety of comorbidities, which need to be considered when caring for this group of persons. Coordination and integration of services for managing all individual diseases is needed in multi-morbid patients in order for care to be efficient, safe, and minimally burdensome.

Minimally disruptive medicine is an approach in which the patient is central. The patient imbalance between workload (“what patient have to do”) and capacity (“what patients can do”) is the central mechanism driving patient complexity. The quality of the Dutch diabetes care is internationally respected, in particular for its multidisciplinary approach. The Dutch Diabetes Federation recommends “customized care”, fitting the contexts of individuals. Understanding the patient context is a prerequisite for care to fit the patient context, and important for adhering to treatment strategies. Shared-decision making and patient-reported outcome (PRO) monitoring are tools to identify the right care.

Part 1: Decision aids for shared decision making

Shared-decision making is often described as being most relevant for decisions in which there is no best option from an evidence standpoint. Despite some ethical and clinical arguments is shared-decision making not yet routine in clinical practice. To facilitate implementation of shared-decision making, decision aids have been developed.

Chapter 2 and 3 describe the protocol and the results, respectively, of a systematic review about decision aids. Most decision aids developed for persons suffering from cardiovascular diseases, chronic respiratory diseases, and/or diabetes are focused on providing information (option clarification) or discussing choices (harms and benefits discussion), rather than on creating empathic conversations. The consequences of leaving out shared-decision making elements, as well as its situation-dependency, in terms of shared-decision making outcomes is unknown and should be studied in future research.

Multiple difficulties were faced during the conduction of this review. These difficulties point towards the need for quality improvement of randomized controlled trials studying decision aid effects, as well as their publications. The new SUNDAE checklist seems to meet this need to a large extent. However, the choice for measurement instruments to use in these randomized controlled trials, as well as the timing of measurements, are not handled by the SUNDAE checklist and needed to reduce the heterogeneity across studies in this field of research. Therefore, a core outcome set for research in the field of decision aids (for persons with chronic illnesses) is warranted in order to compare research findings across studies.

The use of decision aids is not a prerequisite for shared-decision making. Implementation of shared-decision making needs multifaceted strategies coupled with culture change among caregivers, their organizations, and patients. Caregivers should be educated about the importance of creating and fostering a culture of shared-decision making and the skills needed to communicate evidence and its limitation in an understandable way. Patients may be educated as well, and decision aids may play an important role in this.

Besides educating patients and health professionals, other ways to shape an environment that facilitates shared-decision making are among others: 1) an adequate appointment duration, 2) short (or at least flexible) periods between visits, 3) continuity of care, and 4) a system in which the medication choice is driven by personal contexts, values, and preferences of patients. Importantly, shared-decision making should not be seen as a tedious added extra, but as the core of good clinical practice.

Part 2: Patient-reported outcomes

PROs are subjective reports and represent what is most important to patients about a condition and its treatment. They are becoming increasingly important in weighing the pros and cons of a particular medication or treatment regimen. In this way, patient perspectives can be taken into account. Evidence generated from PROs may inform the harms and benefits of options discussed

during shared-decision making conversations by evidence generated by PROs. PROs are originally developed for use in research, but are increasingly used by care providers. By use in clinical practice may patient-reported problems putted on the encounter agenda, and thus may PROs create a starting point for shared-decision making.

Patient-reported outcomes in research

When practicing shared-decision making in type 2 diabetes care, then insulin glargine 300 U/mL may be one of the available options. **Chapter 4** describes the observational OPTIN-D study. The OPTIN-D study found that insulin glargine 300 U/mL is a convenient glucose lowering medicine in persons with type 2 diabetes wishing their current treatment to increase flexibility of injection time and to decrease the volume to be injected. Future studies need to examine the impact of glargine 300 U/mL in persons with type 2 diabetes with a less favorable psychological and medical profile. Furthermore, a controlled study design is needed to draw firm conclusions regarding a causal relationship between initiating glargine 300 U/mL and improved patient-reported medication convenience.

Reducing the burden of hypoglycemia is important to persons with type 2 diabetes as in **Chapter 5** hypoglycemia was found to be associated with higher hypoglycemia fear and diabetes symptom burden, independent of treatment regimen. Prevention and adequate management of hypoglycemia at least deserve full clinical attention. This is true for both persons using oral agents and persons initiating insulin therapy. A minimal clinically important difference for both hypoglycemia fear and diabetes symptom burden is needed to make scores interpretable.

Patient-reported outcomes in clinical practice

In **Chapter 6**, a first attempt is made to improve the interpretability of (domain) scores on the Diabetes Symptom Checklist – Revised (DSC-R). We did so by assessing the associations between (domain) scores on the DSC-R and patient characteristics. Our study found that low mood and likely depression amplify scores on all domains of the DSC-R. This is in particular the case for the fatigue,

cognitive symptoms, hypoglycemic, and hyperglycemic domains. These domains can be regarded as measures of acute diabetes symptoms resulting from fluctuating blood sugars. These findings underscore the importance of attention for and accurate treatment of low mood and depression in clinical practice. The other way around may an excessive burden of fatigue, cognitive symptoms, hypoglycemia, and/or hyperglycemia direct to an underlying low mood or depression.

The relevant associations and their effect estimates may be useful in assessing to what extent a certain symptom burden can be regarded as excessive given certain patient characteristics. However, the associations and their effect estimates need further testing in more diverse patient populations. When using the DSC-R in clinical practice, then it is advised to focus on (changes in) DSC-R scores on domain level.

Before using in clinical practice, future studies should evaluate the content validity of the DSC-R in greater detail. Namely, it may lack relevant items, e.g. regarding itchy skin, increased hunger, sweating, and gender-specific sexual symptoms. Future research may focus on creating reference values or weights for different groups, as well as establishing clinically meaningful differences in diabetes symptom burden.

Besides enhancing the content and interpretation of scores, new data collection technologies (e.g., computer adaptive testing) will facilitate PROs to become part of everyday care. Furthermore, training in the use and interpretation of PROs is needed when aiming for optimal use in routine practice.

Making the right care happen

Importantly, identifying the right care is not enough as it must actually be carried out. Several tools are available to make the right care happen, which is important in preventing a workload-capacity imbalance. When capacity cannot bear the workload, then patients with multiple chronic conditions will just “survive” rather than thrive.