

Why real world outcome information is indispensable in making treatment decisions for Multiple Myeloma

M.M. Garvelink¹, O. de Weerd², P.B. van der Nat¹

¹Department of Value Based Healthcare, St. Antonius Hospital, Nieuwegein, the Netherlands

²Department of Internal Medicine, St. Antonius Hospital, Nieuwegein, the Netherlands

INTRODUCTION

- A multidisciplinary team of Multiple Myeloma (MM) experts was organized to implement value based healthcare (VBHC) principles for MM by monitoring and benchmarking a set of outcomes, processes and costs.
- The choice for MM therapy depends on patient values and preferences with regard to outcomes, and should thus follow a Shared Decision Making (SDM) approach.
- The next step in VBHC is to integrate outcome information to support SDM about treatment options.

Aim: To assess MM patients' and caregivers' needs with regard to treatment decision making and communication of outcome information

MR. K HAS MULTIPLE MYELOMA*



- 66 years old
- Married, with children
- Loves to play piano and go hiking
- He received heavy chemotherapy which was effective, but also caused neuropathy, making it difficult to play the piano anymore.
- Neuropathy is one of the outcomes that is monitored in the VBHC improvement cycle. When doctors are aware of important values and preferences of patients (e.g. that Mr K loves to play the piano), relevant outcomes can be discussed and taken into account in choosing the best available treatment.

*MM is a haematological malignancy in which plasma cells in the blood produce abnormal proteins (M-proteins). MM is incurable, but due to improved treatments the disease has become chronic and patients can survive for several years after diagnosis with alternating sick and disease-free periods

METHODS

- Data collection: 2 group discussions about experiences/needs with treatment decision-making & use of outcome information
- Participants: 11 MM patients (91% male, 71 years old); 10 caregivers (89% partners)
- Analysis: Transcribed discussions were open coded by two researchers and then thematically categorized

RESULTS

Treatment decision-making (DM)

- Positive evaluations of decision-making process (context, people involved)
- Few option awareness
- Patients appreciated that their haematologist decided and explained considerations, which made patients feel involved in DM. No active weighing of values took place.
- Lack of knowledge and confidence to make decisions themselves and trust in the haematologist made it easy to defer the decision to the haematologist:

"well, the doctor has the biggest role in this, right? He knows best. I mean, I cannot choose because I do not know, I do not have the knowledge. [..]"

Communication of outcome information (OI)

- Discussion of OI takes mostly place after treatment has started, when hematologists inquire about experienced side effects in order to decide whether to continue treatment or not.
- OI was based on haematologists' experiences or scientific evidence.
- Participants' goals for OI: 1) weigh outcomes in DM; 2) get insight in their care trajectory; 3) compare with other patients.
- Interest in (more) OI about survival, daily functioning, effectiveness of medication, and quality of life (including social aspects).

"Of course, you are not familiar with all medication. So, when the doctor thinks that something is best, well, than you accept that. But like I said I often got pills, well, then I opened the prescription information... a whole list of side effects! [Which were not discussed]."

CONCLUSION/DISCUSSION

- Why discuss OI?
 - Currently no structured provision of real world OI to weigh in DM.
 - Patients prefer more option awareness, a bigger role in decision-making and more OI.
 - The OI that is in the VBHC-outcome set for MM are in line with patients' information needs. The use of real world OI (derived from VBHC-cycles) is in line with patients information goals.

Conclusion: Discussing real world outcome information as monitored in VBHC improvement cycles is in line with participants goals and needs. Future research should look into how OI can best be communicated

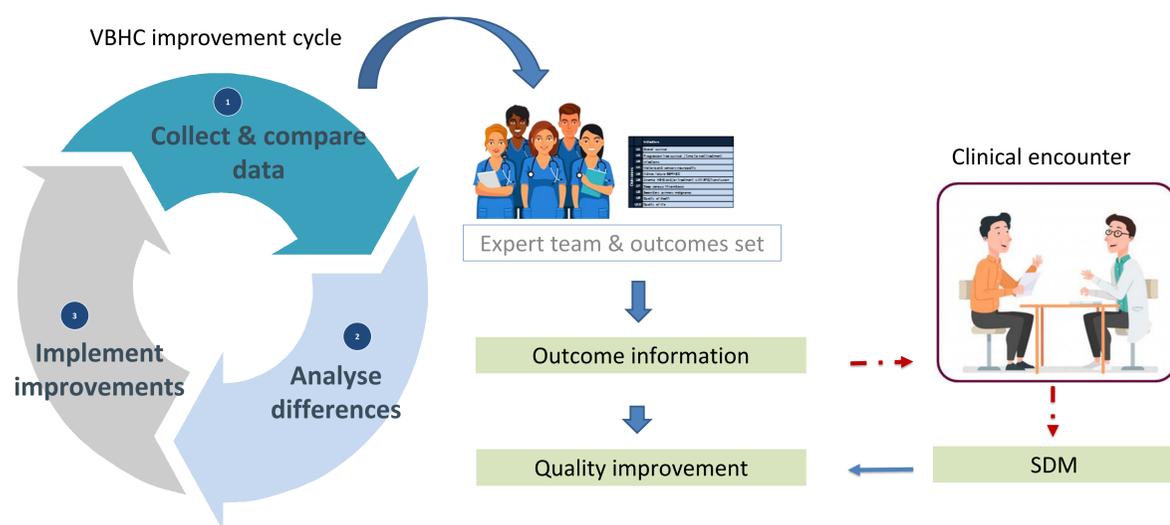


Fig. 1. Graphic representation of how outcome information as obtained in VBHC improvement cycles can influence quality of care directly, and through SDM.

E-mail: m.garvelink@antoniuziekenhuis.nl

St. Antonius Hospital
P.O. Box 2500
3430 EM Nieuwegein
The Netherlands

CONTACT

