A Voice at the Table

Patient participation at the morbidity and mortality meeting

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ISBN: 978-94-6483-129-0

Cover design: Studio FFF

Opmaak: Stefan Geesink en Britt Myren

Printed by: Ridderprint

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Proefschrift ter verkrijging van de graad van doctor
aan de Radboud Universiteit Nijmegen
op gezag van de rector magnificus prof. dr. J.H.J.M. van Krieken,
volgens besluit van het college voor promoties
in het openbaar te verdedigen op

woensdag 28 juni 2023
om 12.30 uur precies

door

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geboren op 13 november 1988
te 's-Hertogenbosch

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Diversity is having a seat at the table. Inclusion is having a voice and having that voice be heard.

- Kadia Tubman

Contents

Chapter 1

general introduction

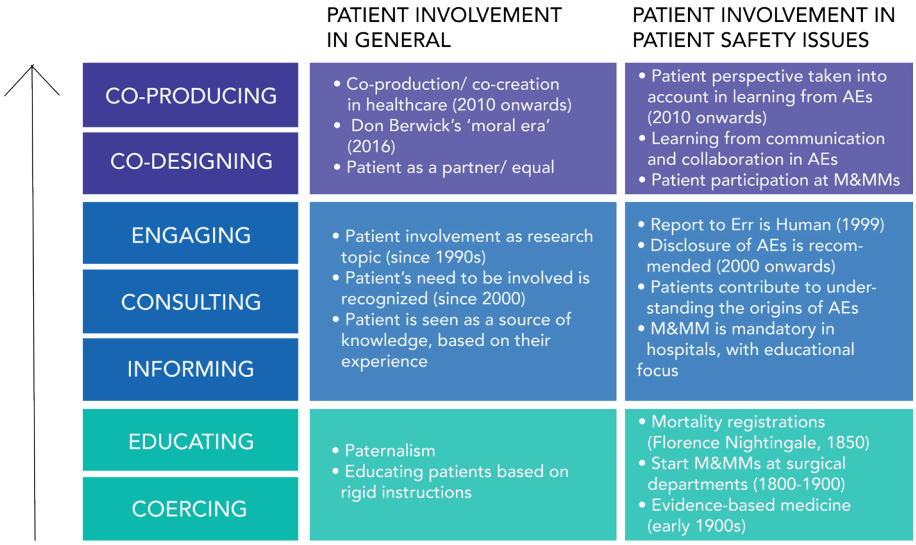
Giving the patient a voice and tailoring care to the patient's needs are important aspects in providing patient-centered care. However, the practice of involving patients as equals or team members in discussions concerning their care remains challenging. How can equality or inclusiveness be achieved in a hospital setting? And what are the challenges for healthcare professionals? Patient involvement can be seen as a strategy to reach patient-centered care; however it may require a different approach to healthcare delivery.(1) The focus in this thesis is a patient-centered innovation to improve the morbidity and mortality meeting (M&MM) at the Radboudumc gynecology department. We introduced patient participation at the M&MM and observed it as an integrated part of quality improvement. This patient-centered innovation gave a voice to patient's experiences and opinions at the M&MM. In order to understand whether patient participation contributes to the intended goals of the M&MM, we evaluated attendees' experiences, explored areas of workplace based learning and designed a guidance for the organization of an M&MM with patients. This thesis takes on practical issues and their (instrumental) solutions, and regards them within the larger context of social dynamics and meeting outcomes.
This introductory chapter outlines different levels of patient involvement, provides views on quality of care and workplace based learning, discusses patient safety issues, and introduces the M&MM. The research questions are presented with an outline of the content of this thesis and the different chapters to guide the reader.

Patient involvement in healthcare

Patients and healthcare professionals communicate each time they meet, yet the way they communicate has changed significantly over the years. Traditionally, the paternalistic approach of healthcare professionals where the 'doctor knows best' was expected and accepted by patients. This has been shifting in recent decades towards greater equality, and more patient autonomy.(2, 3) The different stages and forms of patient involvement can be explained with the participation ladder based on the ladder of Arnstein (see figure 1).(4) This ladder starts with the passive engagement and education

of patients to promote their involvement; this is followed by consulting and engaging with patients; the highest rungs on the ladder are co-designing and co-producing with patients based on figure 1. Currently many healthcare institutions aim to, or recommend, involving patients at on the highest level of the ladder. Patients have a right to information relating to their care and want to be better informed, more involved, and to receive humanized care(5-7) In return, patients' knowledge and experiences are seen as a source of information, valuable for healthcare delivery and improvement. Healthcare professionals have the ethical, professional, and legal obligation to fully disclose what is happening to patients to find a just outcome.(8) However, professionals need to be able and willing to engage with patients because transparency is only achieved when the patient understands the information presented to them.(9) Patient-centered care is described as care that is adjusted to individual needs and personal circumstances, and optimizes healthcare delivery for patients. Don Berwick of the Institute of Healthcare Improvement (IHI) calls the shift to aspects such as patient involvement and transparency 'the 3rd era', or 'moral era' of healthcare. In this era professionals are moving away from measurements and 'risk thinking' - and leaning towards a focus on morals and values important to people.(10) It is important to note that this era also requires professionals to be aware that patients will have their own agency to make choices, and some patients may not wish to be involved.(11) Patients' desire and ability to actively participate in their care may also be influenced by the interpersonal skills and attitude of healthcare professionals.(12, 13) In line with these efforts, the international climate in healthcare is shifting towards more person- and patient-centered care. Figure 1 places general (historical) events that influenced patient involvement, next to patient involvement in patient safety issues.

Figure 1. Participation ladder by Arnstein(4) with contributing (historical) events in patient involvement



Although research provides insight into how aspects of patient-centered care can be achieved, it remains challenging to incorporate equality in the practice of daily healthcare delivery.(20, 21) It requires effort, time and sometimes even tailored attention during the organization and implementation of care by healthcare professionals.(22) This is also related to the fact that patient-centeredness may be perceived differently by different healthcare professionals.(23) Their perception may determine how patients' experiences are taken into account.

Improving quality of care

Involving people and centralizing patients in their healthcare process is recognized 'as a key component in developing high-quality care'.(14, 15) Patient experiences of care are therefore incorporated in a growing number of quality measurements.(16-19) When patient involvement is a key component in developing high-quality (patient-centered) care and improving overall patient care, it raises questions on how quality is defined. Besides the various models and definitions of quality of care, patient-centeredness is acknowledged in the most commonly used definition by the Institute of

Medicine (IOM).(15) The World Health Organization recently adapted the definition by using people-centered instead of patient-centered to define high quality care: "care that is safe, effective, people-centred, timely, efficient, equitable and integrated".(24) However, for a long time patient-centeredness and patients' experiences were not part of how quality of care was perceived by healthcare professionals. Initially, quality of care measures focused on the patient's physical state. This is rooted in the 1850s when Florence Nightingale began to register mortalities in military hospitals. This information provided imperative insights into causes of death for the benefit of soldiers' medical care. Quality of care could be understood and defined by the registration of mortalities and treatment outcomes.(25) The surgeon Ernest Codman (1869-1940), one of the founders of evidence-based medicine (EBM), linked records of diagnostic and treatment errors of individual patients to health outcomes. This furthered the medical perspective on how to improve quality of care, and developed ways to scientifically monitor and evaluate healthcare delivery.(26, 27) Eventually, Codman's ideas shaped EBM and medical knowledge based on scientific evidence was used to solve medical problems and seen as a way to limit the fallibility of humans.(28) EBM lies at the root of medical culture and medical decision making and may therefore influence or determine the way professionals engage with patients.(29, 30) In addition, protocols resulting from EBM may not be applicable in each situation for each patient, as it does not take the patient's context into account.(31) In effect, EBM influences how professionals treat patients and thereby places a debatable weight on the value placed on patient experiences. In the surgical field the ideas of EBM are used to classify negative outcomes by differentiating complications, also known as the 'Clavien-Dindo Classification'.(32, 33) This tool is used in most hospitals for quality assessment of minor to severe complications and mortality, ranging from Grade I to V. Although this classification is commonly used in the case of negative outcomes, or (serious) adverse events ((S)AE) (34, 35), it does not provide insights into errors that may be concluded to be based on the experiences of patients and professionals. The (social) environment where communication or collaboration errors can occur is initially not included in measurements concerning negative outcomes. Leading scientists in the field of healthcare have shifted the notion of quality of care from a sole focus on mortality and later on morbidity, towards taking relational, collaborative and communicative aspects into account. Thus moving from objective measurements of quality towards patient-centered,

subjective and experience-based factors in which the patient is an integrated part of quality.

In the scientific field there are different approaches to improving the quality of care, related to the notion of quality of care adhered to. Implementation science is related to EBM as it takes on underutilized evidence-based practices (EBP) to increase its use.(36) Its systematic approach usually provides generalizable outcomes beyond the individual concerning the adoption of an intervention. This can lead to advice on how to implement an intervention in other contexts as well.(37) Often the outcomes require organizations or people to change in order to start using the intervention correctly. Change itself is an important part in a transition process to improve efforts and innovations, and necessary when adopting a new way of working.(38) This transition process, or adaptation phase, needs to be taken into account while studying implementation processes. However, this is described as a paradox as it aims to institutionalize an intervention in the middle of processes that requires people to change the way they work.(39) Continuous change can rather be translated towards looking at quality improvement as a learning process. On the one hand, because the people in the improvement effort need to learn how to work differently and change their behavior. On the other hand, because people have a personal and changing nature, therefore making the learning process dynamic.(40, 41) Changes can affect the social environment directly and indirectly. Process innovation refers to the technical and administrative aspects of an innovation, while social innovation promotes understanding of how people are affected. This includes not only healthcare professionals, but also patients who can be affected and/or take part in aspects of an innovation. Avelino (2019) defines social innovation as a 'change in social relations, involving new ways of doing, organizing, knowing and framing'.(42)

A quality improvement effort can hardly be looked upon in isolation from social dynamics and can require continuous change leading to improvement. The adoption of a new method, or way of working, may therefore be both technical and social.

Patients are part of healthcare professionals' experiences in daily practice. Therefore, the patient is part of the workplace in which professional learn.

Overall, workplace-based learning is a substantial part of how healthcare professionals are educated, formed during working hours and taught by peers and leading figures.(43, 44) There are examples of patients participating in the workplace, for example in the care team with nurses or in elderly care; however professionals seem to struggle to balance the power to enable active participation of patients and to perceive the patient as a person/expert on their own disease and life.(45-47) Patients are often not recognized or included as part of the work environment in which professionals learn.(48) Research investigating patients' definition of quality of care shows that they see themselves as a part of the care that is provided. Patients expressed that they co-produce, or self-manage, healthcare delivery when they articulate their needs and concerns about the quality of care.(49) This shows that in the context of workplace-based learning interactive dynamics exist around quality of care, in which the patient feels included. In order for patient involvement to be recognized as a valuable part of healthcare delivery, it may require professionals to change their long-held beliefs and ways of working. Research on innovations that include patient participation and underlying learning processes may promote understanding of such a transition.(47, 50-52)

Patient safety

Improvement efforts resulting from the patient safety movement have tried to both measure and lower morbidity and mortality, and to change the social environment in healthcare delivery. Patient safety deals with a broad array of issues that concern healthcare quality. This was incited by the report 'To Err is Human' in 1999 that called for attention to be paid to patient safety issues, definition and classification of AEs, the importance of lowering (s) AEs and urged openness to learning from what happened.(53). In addition, the concepts of transparency and openness have gained more attention in the patient safety context. The term transparency has influenced policies to improve the registration of clinical outcomes and patient access to their medical records. Openness in a healthcare setting refers to the inter-relational aspects within the organization, such as between healthcare teams, in patient-doctor dynamics and to speaking up.(9, 54) Healthcare institutions attempt to operationalize openness in daily clinical care.(55, 56) This includes being open (AE) to - and with - colleagues and patients after adverse events.(6, 57, 58) Openness is also considered as an important way to improve health care.

The focus in the Netherlands has mainly been on the registration of AEs in hospitals and in effect how to lower the incidence of AEs. The Netherlands Health Care Inspectorate ('Inspectie voor Gezondheidszorg') uses the AE registration system as a performance indicator in order to measure quality improvement.(59) These systematic changes seem to have created a blame-free reporting policy and influenced a liberal way of looking at the registration of AEs.(60)

Although efforts in the Netherlands show a decline in AEs and an increase in blame-free reporting, the cases of potentially avoidable damage and mortality remained the same between the period 2011-2012 and 2015-2016.(61) Research by Van der Velden et al. (2020) estimated that in a 1-year period medical errors would affect at least 185.101 persons in the Dutch adult population.(62) This raises questions regarding which factors may be relevant in fostering a decline in AEs. The quality of how professionals deal with, and learn from, AEs needs to be improved. An important factor in achieving quality improvement is to involve patients and to facilitate openness around AEs. The morbidity and mortality meeting (M&MM) aims to discuss and learn from AEs to improve daily clinical practice. That makes the M&MM a suitable setting to study patient involvement and different ways of learning from AEs.

The morbidity and mortality meeting

Historically, M&MMs were implemented in the early 1900s to learn from AEs through regular presentations of autopsy findings. M&MMs are an important part of learning from AEs, recommended by the Institute of Medicine (IOM) and required in graduate training. Worldwide M&MMs have become standard practice in hospitals for most medical specialties. However, research does not provide evidence that the meetings are effective in improving patient care.(63, 64) In order to achieve optimal learning from AEs during M&MMs several suggestions for improvement of these meetings are presented.

Research describes recommendations on organizational improvement, such as standardization of the meeting format, obligatory attendance, multidisciplinary participants and working with a strong moderator.(64, 65) In addition to the organizational recommendations, the M&MM can also be improved by shifting the focus from isolated (technical) issues towards contributing underlying (social) problems, such as communication

and collaboration (see figure 1).(66-70) A proactive approach to safety is understanding everyday practice and gaining insight into underlying aspects why events did not go as planned (Safety-I), but also to moving forward in areas that went well (Safety-II).(71, 72) To understand everyday practice and underlying aspects patients may help improve the overall learning potential of the M&MMs. Although research does provide examples of including the patient perspective at multidisciplinary team meetings(73-75), in most of the literature on steps to improve the M&MM patient participation has not been suggested. However, the patient's perspective can be a valuable contribution when professionals are learning from AEs. Etchegaray et al. (2014, 2016) found that patients and family members can identify contributing factors to AEs, providing new and different insights to possible causes. (76, 77) Patients have a different perception as users and receivers of care, and are usually the only constant factor during the whole care process. Moreover, including patient experiences in identifying causes of AEs may provide answers on why patients file complaints, how to react earlier to signals that may lead to negative patient experiences and how to anticipate issues that are often unknown to professionals themselves.(66) Yet, healthcare delivery cannot be improved if the learning points from the M&MM are not implemented in practice.(78) Research suggests different ways to improve the M&MM and achieve implementation of learning points: integrating a continuous cycle with returning learning points by using SMART (Specific, Measurable, Achievable, Realistic, Timely) goals, or to link PDCA (Plan Do Check Act) cycles to the recommendations.(65, 78) There does not seem to be a standard format for how to incorporate such a cyclical way of checking and reflecting on the learning points resulting from the M&MM.

Although Dutch hospitals have made improvements in the registration of AEs and M&MMs have been introduced in most departments, some professionals still note the persistence of hierarchy and unsafe situations during M&MMs. (79, 80). This may limit the potential of the M&MM to support actual learning. It may take time for a team or organization to change because organizational culture is described as stronger than strategies or policy.(81) Each improvement effort resulting from the M&MM may improve patient care, but also affect how professionals engage with each other and patients on a social and behavioral level.

Aims and outline of the thesis

Although involving patients in an equitable way seems to be complex, it is an integrated part of quality of care and it aligns with changes in the health system towards more openness. Therefore, in order to improve the M&MM, a patient-centered meeting format (M&MM-P) was developed in which patients can participate at the meeting when their adverse event (case) is presented. This thesis evaluated how patients can be involved at M&MMs and took the social dynamics and underlying learning processes associated with adapting to a M&MM-P into account. To that end, we implemented and evaluated new practices in the meeting design, and used ethnographic methods to understand the attendees' beliefs, behaviors, and preferences. In addition, we gained a clear overview of the outcomes of the meetings to grasp the practical benefits. Observations, different interviewing techniques and action research, all grounded in qualitative research methodologies, were used to study change in the context of patient involvement at the M&MM.

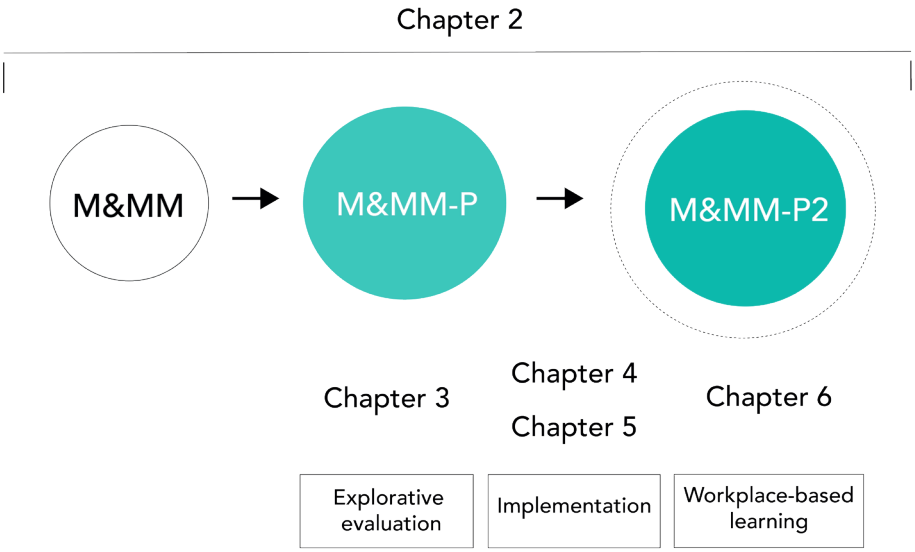
The objective of the thesis was to understand how a patient-centered innovation can be safely implemented in clinical practice, and whether it encourages participants to learn and change their behavior, and achieves improvement in care. This research was conducted at the Radboudumc gynecology department after a patient expressed an interest in attending a M&MM. Collaborative action between professionals in leadership positions at the department made it possible to start this innovative project.
Specific research questions addressed to understand the improvement efforts of the M&MM are as follows:

- What are the experiences of patients and healthcare professionals with an M&MM (in-person and online) with patient participation?
- In what ways do patients and healthcare professionals learn and change their perspectives and behavior from attending M&MMs with patient participation?
- What elements need to be part of the guidance to (safely) implement an M&MM with patient participation?

Outline of this thesis

Involving patients in their own M&MM is the main improvement step addressed by this thesis. Figure 2 provides a visual outline of the chapters in relation each research approach. The disclosure of adverse events (AEs) to patients is an important but challenging task for professionals after an AE. The literature review in **chapter 2** outlines the different factors that are important from the perspective of patients and healthcare professionals to enable the safe disclosure of AEs. There still seems to be a gap between what patients need and what healthcare professionals provide in disclosure communication. **Chapter 3** is an explorative evaluation of the first eight M&MMs with patient involvement (M&MM-P) at the gynecologic department. It presents an insight into the experiences of both patients and healthcare professionals who attended the M&MM-P together. This study shows the practical, organizational and behavioral adaptations necessary to involve patients in their own M&MM. **Chapter 4** describes the experiences of patients and healthcare professionals of inviting patients to attend the M&MM-P via a video conference tool. This was implemented during the COVID-19 pandemic, which pushed online alterations of the meeting design and guidance in the last phase of the research. **Chapter 5** describes the implementation of a cyclic workflow based on the PDCA-cycle at the M&MM-P. Both the practical tool and the reasons for healthcare professionals to successfully execute their assigned actions are presented. Healthcare professionals also face challenges relating to their long-held beliefs and convictions of patient involvement and patient-centered care. Therefore, in **chapter 6** the M&MM-P is studied as a transformative learning experience for professionals who attend the M&MM-P. The multiple experiences of attending an M&MM-P supports a learning process and learning environment (M&MM-P2) on a deeper level that seems to be relevant in order to sustain this innovative approach in other departments in the future. **Chapter 7** discusses the findings in this thesis in relation to further implementation of the M&MM with patient involvement, future perspectives and research.

Figure 2. Thesis outline



Legend.
morbidity and mortality meeting (M&MM); morbidity and mortality meeting with patient participation (M&MM-P); morbidity and mortality meeting with patient participation within a learning environment (M&MM-P2)

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Chapter 2

being open

Disclosing adverse events in clinical practice: the delicate act of being open

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Health Communication 2022;Feb;37(2): 191-201.
doi:10.1080/10410236.2020.1830550.

ABSTRACT

Practicing a 'safe' disclosure of adversremains challenging for healthcare professionals. In addition, knowledge on how to deliver a disclosure is still limited. This review focuses on how disclosure communication may be practiced based on the perspectives of patients and healthcare professionals. Empirical studies conducted between September 2008 and October 2019 were included from the databases PubMed, Web of Science and Psychinfo. After full text analysis and quality appraisal this scoping review included a total of 23 studies out of 2537 studies. As a first step, the needs of patients and the challenges of healthcare professionals with the practice of providing an effective disclosure were extracted from the empirical literature. Based on these findings, the review demonstrates that specific disclosure communication strategies on the level of interpersonal skills, organization and supportive factors may facilitate healthcare professionals to provide optimal disclosure of adverse events. These may be relevant to provide patients with a tailored approach that accompanies their preferences for information and recognition. In conclusion, healthcare professionals may need training in interpersonal (verbal and nonverbal) communication skills. Furthermore, it is important to develop an open (organizational) culture that supports the communication of adverse events and disclosure as a standard practice.

keywords

Disclosure communication; scoping review; open culture; clinical practice; adverse events; interpersonal skills

Introduction

The disclosure of adverse events (AE) is seen as an important ethical and patient safety concern. (1) Adverse events may be due to medical errors, in which case they may be preventable, or to factors that are not preventable. (2) Adverse events are incidents that result from a medical intervention and are responsible for harm to the patient (death, life threatening illness, prolongation of hospital stay etc.). (3) The growing awareness for competent disclosure, fueled by the report 'To Err is Human: Building a Safer Health System' in 2000 and the patient safety movement, (4) led to research on why, who, when and where to disclose. (5) As a result, the healthcare environment has been improved, leading to the development of disclosure policies (6-8) and support systems for healthcare professionals and patients in hospitals. Organizing a 'safe' disclosure could lead to a better patient-physician relationship and may even lower the need to file a lawsuit. (9) However, knowledge on how to deliver the disclosure is still limited amongst healthcare professionals. (10)

The core element of disclosure is open communication. Open communication has been defined as a relationship where both parties experience the other as a willing and receptive listener without negative or nonaccepting responses. (11) Goldsmith framed open communication as an ideology that people refer to within their own lives and relationship. (12) The healthcare context challenges open communication, due to power relations, the use of strong biomedical language, or different knowledge and values that can interfere with the interpretation of what has been said. (13, 14) Therefore in situations such as the delivery of bad news, or end-of-life communication, the importance of effective communication is stressed for it can negatively affect the patient-physician relationship and may lead to misunderstandings. (15) The interaction between patient and physician during disclosure in case of an AE may require specific communication skills and work environment. (16, 17) Despite the fact that healthcare professionals agree that open communication is important and the patient should be given honest information after an AE (18), not all AEs are fully and/or honestly disclosed. (19, 20) This may be related to the effect the AE can have on the involved physician in terms of a fear of litigation, trauma as the second victim, or other barriers to engage in transparency. (10, 21-23) In order to foster openness and honesty, the term

'open disclosure' has been adopted into different policies and guidelines such as Open Disclosure Standard in Australia, the UK and Canada. (24) However, recent research suggests a need to understand how healthcare professionals should interact and which skills or contextual factors, are important to foster open communication.

In the context of surgical care, surgeons are generally the healthcare professionals who have the task of disclosing AEs to the patient. (25, 26) Surgeons are often unprepared and during the regularly organized morbidity and mortality meetings (M&MM) AEs are in general discussed amongst staff members, excluding the patient. These meetings often focus on technical or individual points of improvement, while the causes of AE can also lie in communication errors, team or system failures. (27-29) In effect, these traditional M&MMs do not provide surgeons with the proper communication tools to practice disclosure and discuss the AE with the patient. (30) In the current healthcare era where open communication and person-centered care are prioritized it would be beneficial for physicians to acquire skills in order to foster effective communication about AEs with the patient.

Therefore, this scoping review aims to describe which interpersonal and contextual factors are relevant to how disclosure communication may be practiced. The first step in formulating how disclosure communication may be practiced, is to understand the perspectives and experiences of patients and healthcare professionals with disclosure. This review selected empirical papers on the perspectives of patients and healthcare professionals with the communication of adverse events in a clinical setting.

Materials and methods

Research design

We performed a scoping review which is a technique to map relevant literature raised from a broad theme, representing different study designs. (31) The items of the PRISMA checklist were included and used during the literature review process. (32)

Databases and search criteria

Although research on different aspects of the disclosure process slowly started since the report in 1999 'To Err is Human' (4), we focused on the most recent literature of the past decade: between September 2008 and October 2019. The databases PubMed, Web of Science and Psychinfo were used to identify studies on disclosure communication.

The search was executed using the broad terms 'adverse event', 'disclosure' and 'patient' or 'physician perspective'. The search term 'adverse event' included, medical error and near miss. See appendix for an overview of the used MESH terms. An information specialist of the medical library assisted in the online search. Google scholar was consulted to explore other relevant articles, citing the research included from the primary databases. Additional literature was found by hand-searching after consulting the references of the included articles.

The inclusion and exclusion criteria were assessed in an iterative process during the selection of studies. During this iterative process it was possible to add or remove criteria that were unknown at the start of the review. The included original studies all referred to interpersonal aspects of disclosure of AE related to the interaction or communication between patient and healthcare professional. Studies that describe contextual factors that influence communication strategies during disclosure were also included. Only studies originated from Western countries in Dutch or English-language with available PDF were included.

The excluded articles focused on internal reporting, public reporting or reporting to professional or regulatory organizations, disclosing errors among team members and the impact of testing a framework, method or training of disclosure. Furthermore, personal accounts, reviews, letters, editorials, opinion pieces and commentaries were excluded. In case of multiple included studies by the same author, the quality and overlap of data was verified and excluded when similar data was used.

Quality assessment and synthesis of the studies

The literature was selected and interpreted by BM and SB. The inclusion and exclusion criteria were first assessed separately by title and abstract selection

using the open software Rayyan QCRI. (33) The reasons for the researchers to include or exclude studies were described in the program. Upon agreement, studies were included for full text screening based on the including and excluding criteria (see an overview of the selection procedure in figure 1). The quality of the literature was assessed with the Critical Appraisal Skill Program (CASP) Checklist for qualitative research and the Axial tool of the British Medical Journal (BMJ) was used for cross sectional observational studies and surveys. (34, 35)

Data synthesis was performed in Windows Excel, where conclusions drawn from the empirical evidence of the studies were extracted and re-framed into main categories. As a first step to outline how disclosure may be practiced more effectively, the perceived and experienced needs of patients and challenges of healthcare professionals were categorized. The main categories to frame the patients' needs and the healthcare professional's challenges were based on previous studies and different guidelines. This resulted in seven important stages of disclosure. (36-38) These stages were: pre-disclosure and preparation, notify the patient of the error, explain what happened, apologize, acceptance of responsibility, description of steps to be taken to alleviate harm and better the situation, and assurance of an investigation to prevent recurrence and learn from them.

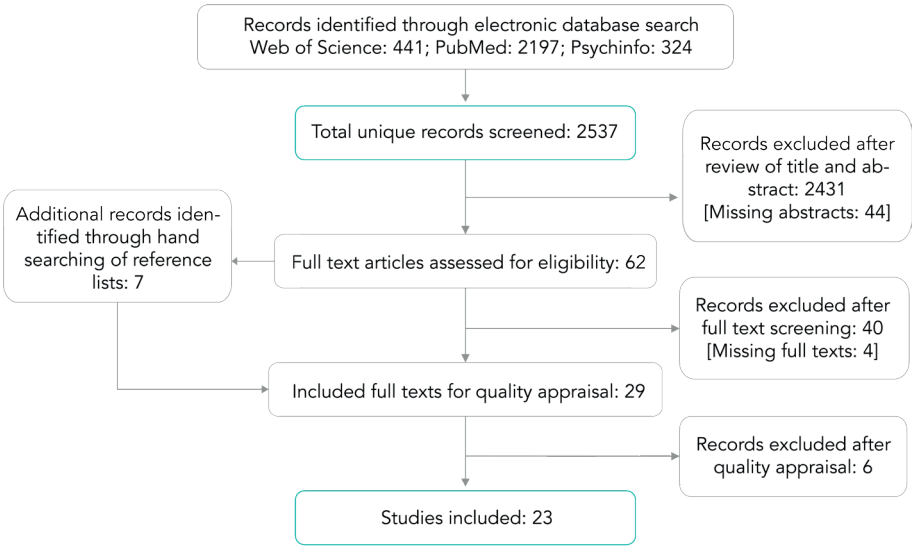
Based on the results of this first step in the analysis we framed the data into new categories of skills and contextual factors that are important for the practice of openly communicating a disclosure.

Results

Article retrieval

The total unique records retrieved from the databases was 2537. The title/abstract and full text screening were performed with the inclusion and exclusion criteria leading to 22 eligible studies. In addition, 7 records were identified through hand searching of the reference list. Finally, 29 studies were eligible for quality appraisal of which six were excluded because of a lack of empirical evidence, unclear aims or goal of the study, or lack of reflection on the development of the study. In total 23 studies were included in the review, as shown in figure 1.

Figure 1. Search and selection process of the included studies



Studies included in review

The included studies employed diverse study types: (a) simulation study with video vignettes (b) surveys with written vignettes (c) survey with personal experiences (c) interview studies and focus group studies, and (d) case studies. See table 1 for an overview of the different study designs. The survey and simulation study results were interpreted and analyzed statistically while interviews and focus group studies were analyzed using (thematic) content analysis. The authors had diverse backgrounds ranging from communication science and psychology, ethics, medicine, law, and policy in the field of safety and quality of care. One study based their results on how surgeons described their experiences of disclosure, instead of studying how healthcare professionals act. (39) Two authors were both the primary author in respectively six and four studies: Hannawa (40-45) and Iedema (46-49). Hannawa performed different studies that build on the validation of the Medical Error Disclosure Competence (MEDC) model. (43, 44) Four studies evaluated disclosure communication in a context where Open Disclosure policy was implemented. (24, 47-49) The number of participants ranged between 1 to 721, of which fourteen studies involved patients and family members, eight studies involved healthcare professionals (surgeons, nurses and clinicians) and one study used psychology students to score communication behavior of healthcare professionals.

Table 1. Included articles and its characteristics based on year of publication

Author	Type of study design	Participants	Data collection approach
Iedema, R et al. (2008) (49)	Interview study	23 patients and family members involved in adverse event and incident disclosure	23 semi-structed, open-ended interviews
Iedema, R. et al. (2009) (50)	Interview study	131 health care staff from across 21 hospitals (anaesthetist, registered nurse, patient liaison officer, midwife nurse, nurse manager, director health service)	131 semi-structured interviews, in-depth (45 min to 120 min)
Shannon, S. E. et al. (2009) (51)	Focus group study (n=11)	96 registered nurses	Recording of 11 focusgroups
Mazor, K. M. et al. (2009) (52)	Interview study	17 patients and family members that experienced an AE	Semi-structured phone interview
Wu, Albert W. et al. (2009) (53)	Video vignettes. 5 variations based on apology and acceptance of responsibility, three types of adverse events ((1) missed mammogram, (2) chemotherapy overdose, (3) delay in surgical therapy)	200 volunteers from general community	Survey (likert-scale)
Hannawa, A. F. (2011) (54)	Simulation study. Hypothetical disclosure to a standardized female and male patient	30 attending physicians	Video recording of 60 disclosures and coded and rated on likert-scale. Apology and general communication skills rated.
Iedema, R. et al. (2011) (55)	Interview study (retrospective) (n=100)	39 patients and 80 family members who were involved in high severity healthcare incidents (leading to death, permanent disability, or long-term harm) and incident disclosure	119 semi-structured in-depth interviews
Iedema, R. & Allen, S. (2012) (56)	Case study. Replicated single-case approach. Evaluation of incident disclosure experience	1 wife of the patient	One in-depth interview (video recorded, 150 min).
Mazor, K. M. et al. (2013) (57)	Interview study	78 patients who believed that something had gone wrong during cancer care	78 in-depth interviews
Hannawa, A. F. (2014) (58)	Video vignettes. 2 variations: (1) verbally effective and nonverbally involved error disclosure. (2) verbally effective but nonverbally uninvolved error disclosure. 7 effectiveness criteria: presence of apology, sincerity of apology, physician's remorse, explanation of error, severity of error), fault attributions, intentions to switch doctors	216 hospital outpatients	Survey (likert-scale)

Allan, A. et al. (2015) (59)	Video scenarios with components of (1) basic self- focused apology (admission, regret, restitution) (2) complex other focused apology (basic and acknowledgement, remorse, reparation)	247 community members	Survey (likert-scale)
Watson, B.M. et al. (2015) (60)	Study 1: 8 videos of effective (n=4) and ineffective (n=4) disclosure rated by psychology students (n=80) Study 2: discourse analysis of transcripts from 8 recordings (immediate topic repetition, topic consistency other, topic consistency self)	8 recordings of clinicians performing open disclosure to an actor in a training program	Study 1: Survey Study 2: Discursis analytic technique
Leone, D. et al. (2015) (61)	Simulated encounter with a patient/ family member while communicating: clear responsibility error, or shared responsibility error. Coded for mentioning of term 'error ' and apology	38 clinicians	Simulations were coded with Roter Interaction Analysis System (RIAS)
Elwy, A.R. et al.(2016) (62)	Reports of disclosure of adverse events surgeons experienced themselves, within 30 days of the original surgery	67 surgeons, representing each of the 12 surgical specialties	Web-based survey
Hannawa, A. F. et al. (2016) (63)	Video vignettes. 3 variations: (1) high nonverbal involvement (2) low nonverbal involvement (3) written vignette without nonverbal information	318 outpatients	Online survey with forgiveness-related self-report measures.
Harrison, R.et al. (2016) (64)	Retrospective study based on analysis of data collected in 2014	1087 front-line healthcare professionals from hospitals and primary care	Web-based survey
Carrillo, I. et al. (2017) (65)	Focus group (n=10) in 5 hospitals. Test communication science model for disclosure communication	63 patients	Focus group recording
Hannawa, A. F. (2017) (42)	Interview study	13 doctors and 22 nurses in range of levels and specialties from hospitals and primary care	35 semi-structured interviews
Mira,J.J. et al. (2017) (66)	Focus group/ Metaplan (n=1)	15 medical professionals and 12 nurses (13 worked in hospitals)	Focus group recording
Moore, J. & M.M. Mello (2017) (67)	Interview study	56 patients and 6 family members, 12 district health boards administrators, 5 lawyers specialising in accident compensation corporation (ACC) claims and 3 ACC staff	82 semi-structured interviews, key informant interviews
Hannawa, A.F. & R.M. Frankel (2018) (68)	Video vignettes (n=16) including high/low apology, high/low non-verbal skills and high/low interpersonal adaptability. Context: high severity and low severity	721 current or former patients (treated within the past 3 years)	Survey
Hannawa A.F. (2019) (43)	Questions (n=23) about an experience of a disclosure of a medical error focusing on: skills, adequacy and effectiveness (elements of the MEDC model)	193 patients who experienced an error disclosure during the past five years	Web-based survey
Jones, M. et al. (2019) (69)	Focus groups following simulation training	26 nurses, 24 pharmacists, 41 physicians	Focus group recording

General outcomes

All the included studies approached disclosure as an interaction in which specific communication competences were needed due to the complexity of healthcare and the associated problems around AEs. A study from 2019 showed that disclosure remains rare: one in four patients experienced an AE in the past five years, but only a third received a disclosure. These were AEs not only in a hospital setting, but also private practice, dentistry and pharmacy. The physician who committed the AE was involved during half of the disclosures. (43) AEs in these studies were referred to as: (harmful) medical error, healthcare/ patient safety incidents, injured by healthcare and (un) avoidable adverse event.

Tabel 2 presents the needs of patients and the challenges healthcare professionals face within the different stages of disclosure. Studies show that the disclosure gap still exists because patients' expectations of disclosure are not met.

In the stage prior to disclosure patients need constant communication, informal discussions and a well prepared disclosure. On a more specific interpersonal level, studies describe the importance of sincerity, openness and nonverbal communication. Next to that, patients prefer healthcare professionals to be specific about what actions will be taken to alleviate harm and to see how professionals learned from the event. Most research shows an apology is required by patients, preferably as soon as possible. One study concluded patients prefer an 'other focused apology' where acknowledgement, remorse and reparation is included. Patients' pursuit of a lawsuit does not change after a verbal apology. (59) However, when the apology is inadequate it could lead to a distance and the relationship may deteriorate. The disclosure may be performed by meeting the patients' needs and focus on reconciliation in order to heal relationships, instead of (only) reaching a (financial) resolution. (40, 43, 70) Moreover, when the disclosure is effective and patients perceive the error as understandable, they will experience it as enhancing the relationship. (44, 52)

Table 2. Elements and stages of disclosure: patients' needs and healthcare professionals' challenges

Elements of disclosure	Pre-disclosure and preparation	Notify patient of the error	Explanation of what happened	Apology (sincere)	Acceptance of responsibility and accountability	Description of steps to be taken to alleviate harm and better the situation	Assurance of an investigation to prevent recurrence and learn from them
Patients: needs and expectations	Informal discussions, constant communication (49, 50, 64) More and open communication after a non-preventable AE (52) Expect well prepared healthcare professional(s) (55)	Be forthcoming about errors and AE (52)	Tailored amount of information (42) The explanation is not just for emotional needs, but also to be informed (52, 57) Adequate nonverbal involved disclosure: may enhance the relationship (43, 58)	Sincere, honest, full apology (43, 50, 53) Nonverbal involvement shows sincerity (58) Important: > Face to face >Acknowledge-ment > 'Bad apology' can do harm (43, 67) > Share pain (50) Apology with admission and explanation (42, 57) Verbal apology is not enough, can be misinterpreted (43, 68)	Admit to repeated communication failures, inappropriate behavior and assume responsibility of error (42, 56) Acknowledgement of responsibility for event or error (57, 69)	Action should be congruent with words of apology and caring (57) Expect follow-up and tangible support (49, 55) Expect relational recognition, maintaining relationship and reparation as priority (42) Patient expected input when time was ripe for closure (55)	Respond when patients or family members are concerned with preventing recurrences (57, 67) Action and information of clinician learning and improvement process (55, 57) Reassurance that competent care of patient is top priority (52)

Healthcare professionals: challenges	Which information should be recorded in patient clinical history (66) Whether disclosure should be made on incidents without damage (66) Moral distress when not included in disclosure discussions (nurse) (51) Disclose promptly, as soon as possible, and not too informal (42, 49, 66, 67) Prior knowledge of, or experience with, litigation cases (64, 65)	UAE: no barriers or relevant difficulties (66) AAE: reason to avoid disclosure when litigation is likely (66) More difficult when negatively affected by AE (surgeon) (62) Only half of the disclosures were attended by the clinician(s) who committed the error (43) Fear of lawsuit increased when organization did not usually inform patients (65)	To discuss whether event was preventable (surgeon) (62) One-on-one setting: difficult to speak for someone else and provide factual information (69)	Fearful of litigation when implications of giving an apology are not always clear (61) Fear of losing professional reputation and lack of support (65, 66) Challenging communication item (surgeons) (62) Unclear when apology should be offered (depends on AE) (66)	Nurses are more fearful of punitive action (64) Clear responsibility of the AE: physician communicated more patient-centred, emotional and attentive (65)		Challenging to discuss how recurrences of event could be prevented (surgeon) (54, 62)

Legend:

AE: Adverse Event; **UAE**: Unavoidable Adverse Event; **AAE**: Avoidable Adverse Event

Studies on the experiences of healthcare professionals with disclosure communication mainly focused on the challenges or barriers they face. Healthcare professionals did not experience barriers or relevant difficulties when they needed to disclose an unavoidable AE (UAE). When there was a clear responsibility of the AE, the physician communicated more patient-centered, emotional and attentive. (61) Studies indicated that surgeons experienced challenges to disclosure when they were negatively affected by the AE, and/or the event was avoidable, or when a punitive culture exists. (39, 71, 72) Other challenges arose during the pre-disclosure stage, such as which type of information should be recorded and whether disclosure should be made on incidents without physical damage to the patient. Nurses may feel distress while carrying for the patient when an AE has not been fully disclosed to the patient yet. In general, team disclosures were valued more as it provided moral and informational support for healthcare professionals. (73) An individual setting was appreciated by professionals because it may provide a higher chance of establishing a relationship. The current practice of disclosure showed that taking responsibility and providing a sincere apology can be difficult. The Open Disclosure policy offered opportunities to learn about how to prevent an AE from occurring again.

The overview presented in table 2 shows what both patients and healthcare professionals needs and challenges are in order to effectively practice disclosure. Based on these findings, we will outline strategies on how to practice a safe and effective disclosure.

Interpersonal skills, organization and supportive factors

The empirical data from the studies in this review may inform the practice of disclosure communication on three levels: interpersonal skills, organization and supportive factors (contextual factors). (table 3)

Table 3: Disclosure strategies for healthcare professionals*

Interpersonal skills
Communication - Shared dialogue - Avoid medical jargon - Positive nonverbal use (e.g. eye contact, sincerity) - Active involvement of patients - Do not avoid delicate issues - Be respectful - Reflexivity
Adaptability - Ability to change your view - Adopt words, concepts and perspective of patients - Let the patient (partly) be in control of topics - Interpersonal adaptability
Tailored approach - Be familiar with patient's history - Be aware of patients' needs - Consider the individual impact: o Create space to show emotions and ensure emotional debrief o Take patient seriously, acknowledge what happened o "Other focused apology" - Include acknowledgement, remorse, reparation - Invest in the relationship, focus on reconciliation
Organization
Include the whole team (staff originally involved, nurses/trained nurse managers) Invite care companion or neutral third party Avoid corridors and secure privacy Disclose promptly, as soon as possible Support patients to report errors Show actions and evidence of clinician learning Take action and reassure that competent care of the patient is top priority
Supportive factors
Culture of openness Presence of role models and guidance, leadership by example Guidelines and support on an organizational and institutional level Positive past experiences of disclosure Training for healthcare professionals and system learning

*The strategies described in this table are based on the meta-analysis.

The interpersonal skills are related to the soft skills of healthcare professionals. A (continuous) dialogue and a tailored approach in disclosure communication is important. Interpersonal adaptability can be practiced by using similar words as the patient and to talk about the topics the patient wishes to talk about. (60) It is important for healthcare professionals to be aware of their role during disclosure and practice reflexivity. Healthcare professionals should be aware of how they say something because patients can interpret or experience the disclosure conversation differently from what has been actually said.

The context in which disclosure is being practiced may have an impact on whether healthcare professionals feel comfortable and able to practice open disclosure, and whether healthcare professionals are motivated to practice disclosure regularly. In terms of the organization of disclosure in a healthcare setting, the whole team may be involved during disclosure to provide all the necessary information, and care companions or a neutral third party may be invited to provide support for the patient. For example, nurses play an important role in emotional support at the ward, but do not always feel free to speak openly during disclosure. (24, 73, 74) They need more support from physicians, as well as their (nurse) manager for improvement. Furthermore, healthcare professional should take action and support the patient to report errors. However, healthcare professionals need training in how to provide a disclosure that satisfies patients and supports them in overcoming any challenges or fears. Supportive factors that seem important to achieve the latter are, for example, learning tools and guidelines that are provided on an organizational and institutional level. (44, 47, 49, 70, 72) Other supportive factors are related to personal past experiences of healthcare professionals. (39) Negative experiences may impact whether or not professionals feel comfortable enough to disclose the AE to the patient, and therefore may influence the openness within the organizational culture. (71) The presence of role models and leadership by example also seem to be important to support a culture of transparency to practice open disclosure. Shannon (2009) suggests a role for nurse managers in that process. (74) However, changing or influencing a (organizational) culture is complex and it takes time. A barrier to move towards an open culture may be a punitive culture, or negative consequences, when acting ethically and inform patients. (71) The MEDC guideline Hannawa outlines provide a clear overview of aspects that can be assessed, taught and learned by healthcare professionals, such as adapting

their communication to the expressed needs of patients during the disclosure instead of referring to a standardized message. (43)

Discussion

This review gives an overview of what is important for patients and healthcare professionals when communicating a disclosure. Disclosure communication in an open and transparent way can only be practiced when healthcare professionals require skills on an interpersonal level and consider contextual factors, described in this review in a list with points that deserve attention. Patients need a tailored approach that accompanies their preferences for information and recognition, and to express their emotions and concerns. However, full and timely disclosure with the right skills remains challenging for both healthcare professionals and patients. This is related to the disclosure gap between patient and healthcare professional that still exists. The context wherein disclosure is practiced needs to provide the right climate, access and support to communicate disclosure effectively. There is a clear need to train professionals with proper interpersonal skills, work towards an open organizational culture that supports open disclosure and obtain organizational or managerial support such as clear guidelines and role models. Team disclosure, a care companion and the involvement of nurses is important to reach better disclosure and satisfied patients after disclosure.

Although the ethical and moral obligation to disclose errors is acknowledged in current medicine, the reasons for not disclosing an AE cannot only be sought in a fear of litigation or loss of professional reputation. (22) For a long time AE's were not disclosed because it can have possible negative impact on patients' emotional well-being, especially when complete recovery after a severe AE appeared to be impossible. (71, 75) The AE can also impact the professional as a second victim on a psychological or emotional level, making it difficult to openly communicate a disclosure. (76, 77) In addition, when professionals do practice disclosure it is important they know how to do it. Studies show that a poorly executed disclosure can have repercussions for the patient's wellbeing. When professionals attain such a skillset and become aware of what is important for an effective disclosure - it may support them in overcoming their fear of being sued. (78)

The majority of studied literature advised that healthcare professionals should be trained in disclosure communication even though medical communication has been given a larger role in today's medical education. (79, 80) A growing amount of literature describes how training of disclosure communication can be achieved. The debriefing method, originated in the military, has been incorporated in simulated training and in daily practice for surgeons. (81) Guidelines have been developed to support physicians in handling disclosure, such as the 'Mistake Disclosure Management Plan' beneficial in the early stages to prepare for disclosure. (82) Other studies suggest that during such educational endeavors it is important to provide a context where mistakes can be made and a learning culture is promoted. (83) This indicates that it is important to teach students how to embrace error from the start of their medical training and this may be integrated into the curriculum. (84)

An open culture is important to install disclosure as a standard practice. Literature on safety culture refers to the perceptions of members of the organization on what safety in healthcare means, and the organizational commitment to reach safe care on all levels of the organization. (85, 86) This indicates that it is also part of the role of managers and people in a supervisory position to establish a safety culture . An open (organizational) culture may function in a similar way. Such role models can provide leadership by example and can influence the open communication or safety behavior of healthcare professionals. (24) Professionals in leadership positions may refrain from a punitive culture and support the idea of a 'just culture' to encourage open and honest communication. Aspects of a just culture are learning from mistakes without asking the question of guilt; coaching instead of punishing; and create clarity about the often unclear boundaries between acceptable and unacceptable behavior and who determines this. (87, 88)

A strength of the review is the focus on recent studies, that increasingly focus on how a disclosure should be performed. It provides an overview of the different stages of disclosure and what is known within these specific stages. Furthermore, the review benefitted from the multidisciplinary research team (health care professionals and social scientists) to interpret the literature. This study also holds a few limitations, such as the amount of abstracts (n=44) and full texts (n=4) which were not located or were written in a foreign language. The methodologies of the included studies are simulations, vignettes or prior

experiences, all to re-enact a real-life situation. This is related to the challenges of studying a disclosure, because doing research on interactional behavior of healthcare professionals could affect patients. The studies with simulated patients or actors might have gotten different results in real-life situations. The studies that used descriptions of prior experiences of communication, may have lost important details of that interaction. Research showed that the human recall of communication behavior, or whom they communicated with, can be quite weak. (89) On the other hand, events that trigger strong emotions may positively support the memory. (90)

This review supports a context in which leading figures function as an example of open communication, in order to develop a strong practice of disclosure in a healthcare setting. This can only be achieved if the institution provides training of disclosure communication skills of healthcare professionals as well. In addition, it is important that healthcare professionals are aware of the interpersonal skills and contextual factors that may facilitate open communication, for example when suggesting involvement patients at an M&MM to discuss AE together. (26) Further research is needed that observes 'real life' interactions of trained healthcare professionals and patients. In addition, a study that focuses on how people learn how to master disclosure skills might be relevant in order to understand how disclosure communication skills can be taught more effectively. The results of the review are useful for the practice and development of a training module for healthcare professionals.

More attention is needed on an interpersonal, and contextual level to make disclosure a standard practice in clinical care and bridge the disclosure gap between healthcare professionals and patients. This review resulted in a list with points that may be considered by healthcare professionals. Both in the delivery of bad news and during disclosure it is important to use appropriate (non)verbal language, show empathy, use comprehensive language and listen carefully. In both deliveries physicians may experience a fear of being blamed, or of the patient's reactions. However, the main differences are the emphasis on a proper physical space when delivering bad news and giving hope. (91, 92) Only one article in our literature review specifically mentioned the importance of space to secure privacy during disclosure. (72) The empirical research on disclosure focuses on providing an effective apology and how to prevent an AE from happening again in the future. (43, 48, 93)

Both could be seen as a way of giving hope, however, giving hope is not mentioned as an element of disclosure communication. Active involvement of patients and a continuous dialogue after an AE might be beneficial to provide a tailored approach and meet the patients' needs. The practice of open communication, and eventually a culture of openness, may be possible when training in disclosure communication is offered and professionals feel comfortable to talk openly about AEs.

Disclosure statement
The authors have nothing to declare.

Funding
No external funding.

Data availability statement
The data that support the findings of this study are available from the corresponding author upon reasonable request.

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Appendices

MESH terms search for PubMed

Publication date from 2008/01/01

Search ((“Medical Errors”[Mesh] OR Adverse event*[tiab] OR Calamit*[tiab] OR Medical harm*[tiab] OR Medical error*[tiab] OR Medical Mistake*[tiab] OR Wrong-Procedure Error*[tiab] OR Wrong-Site Surger*[tiab] OR Surgical Error*[tiab] OR Wrong-Patient Surger*[tiab] OR Critical Medical Incident*[tiab] OR Medical Critical Incident*[tiab] OR Never Event*[tiab] OR Medication Error*[tiab] OR Near Miss*[tiab] OR Close Call*[tiab]))
AND Search ((“Disclosure”[Mesh] OR “Communication”[Mesh] OR Disclos*[tiab] OR Communicat*[tiab]))
AND Search (“Physician-Patient Relations”[Majr] OR “Nurse-Patient Relations”[Mesh] OR “Patient Rights”[Mesh:NoExp] OR “Attitude of Health Personnel”[Mesh] OR “Patient Satisfaction”[Mesh] OR Physician-Patient Relation*[tiab] OR Doctor Patient Relation*[tiab] OR Nurse-Patient Relation*[tiab] OR Patient Right*[tiab] OR Patient’s Right*[tiab] OR Patients’ Right*[tiab] OR ((Attitude*[tiab] OR satisfaction[tiab] OR preference*[tiab]) **AND** (physician*[tiab] OR patient [tiab] OR patients[tiab])))

OR

Search ((“Medical Errors”[Mesh] OR Adverse event*[tiab] OR medical error*[tiab]))
AND Search ((“Disclosure”[Mesh] OR Disclos*[ti] OR Disclos*[ot]))

chapter 3

new perspectives

Openness to new perspectives created by patient participation at the morbidity and mortality meeting

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Patient Education and Counseling 2021; 104(2): 343-351.
doi:10.1016/j.pec.2020.08.008.

ABSTRACT

objectives

Morbidity and mortality meetings (M&MMs) at surgical departments may improve when patients participate, leading to different learning points. A gynecological oncology department invited patients to join their M&MMs. The practical constraints and experiences important from the perspective of patients and their healthcare professionals were evaluated.

methods

Semi-structured interviews were conducted with patients and professionals who attended M&MMs at a gynecological oncology department between 2016 and 2018. The interviews were transcribed and coded and thematic content analysis was performed.

results

Eight patients and 17 healthcare professionals participated. Eleven themes related to interpersonal dynamics. The five shared themes are: patient–doctor relationship, language, openness of communication, learning and personal impact. All participants suggested maintaining the new practical design of the M&MMs.

conclusions

Patients and healthcare professionals valued patient participation in the M&MMs. Patient participation is possible when professionals are open to discussing and learning from adverse events (AEs). In this setting, patients feel that they are taken seriously and gain a better understanding of the course of an AE.

practice implications

Involving patients in M&MMs led to new insights, better understanding, and improved processing of AEs. Collaborating with patients and using their feedback seems to be effective when developing innovations in healthcare.

keywords

healthcare quality improvement; morbidity and mortality meeting; patient participation; patient-centered care, qualitative research; learning; open communication

Introduction

Patient participation and engagement better meets patients' needs, preferences and values and thus improves the quality of care. However, involving patients in daily practice challenges today's healthcare and notions of quality. (1-7) Research showed that difficulties in achieving patient participation may be related to factors experienced by professionals, such as lack of time, personal beliefs or lack of perspective taking. For patients it may be related to the acceptance of the new patient role that may influence their willingness to participate. (8, 9) It is known that patient participation can add new perspectives, such as in the field of error prevention where patients add new and different perspectives to the analysis of adverse events (AE). (8, 10-13) Nevertheless, it is not common practice to involve patients at morbidity and mortality meetings (M&MM) where AEs are discussed amongst healthcare professionals. Involving patients in this new healthcare context may challenge the current system and require a different approach of participation. (14)

Around 10% of an approximate 421 million hospitalisations lead to AEs in medicine worldwide every year, especially in surgical care where AEs account for 16% annually. (15) AEs result in unintended patient harm from either healthcare management, intervention or omission. (16) To improve patient safety in surgical care, M&MMs were implemented and aimed at learning from choices and actions that lead to AEs. This is part of the ongoing professional practice evaluation that ultimately leads to improved healthcare and patient outcomes. (17-19) Studies show the need for M&MM quality improvement, because it is difficult to share learning points throughout the organization and achieve practice change. (20-22) As patient participation positively influences patient safety and quality of care, engaging patients in M&MMs might enhance workplace-based learning and practice change. In addition, healthcare professionals may provide more person-centred care as a result. Literature about patient participation at M&MMs is scarce despite the valuable studies about patient participation in other contexts, such as multidisciplinary team meetings. (23-25) Therefore, it is necessary to study (and develop) a new design of the M&MM that includes patients and to encourage learning of adverse events.

Nevertheless, suggesting patient participation at the level of joining the discussion of an M&MM is challenging because it can trigger unsafe feelings and impede an open discussion. AEs can have grave consequences for the patient's physical and emotional recovery, and for the consultant's personal trauma as the "second victim" or due to a fear of litigation. (15, 26-30) However, patients seem to want to be informed, and competent patient-doctor communication seems to be needed after an AE. (31, 32) A joint M&MM with the patient and their healthcare professionals may positively help facilitate mutual understanding and lead to a better patient–doctor relationship and greater patient satisfaction. By changing the practice of M&MM it is possible to study how patient participation in this new healthcare setting can be realized.

The aim of this study was to explore how patient participation at an M&MM can be practiced and whether and how professionals and patients can learn from AEs to achieve practice change. Therefore, we examined practical constraints and experiences from the perspective of patients and their healthcare professionals. This feasibility project was a first step in our design based research approach to study patient participation at the M&MM.

Methods

Study design

We used qualitative research methods, including semi-structured interview guides to understand the topics that were important from the perspectives of patients and healthcare professionals. We used several in-depth interviewing techniques: words appropriate for the participants, open-ended questions, probes and verification information during the interview when necessary. (33) These methods provided tools to explore experiences in a new context of patient participation.

This is the first study of a larger project to optimize patient participation at the M&MM. We used research methodology of design-based research and its principles to test the intervention of patient participation at the M&MM and further develop the design. This study evaluates the first design of the M&MM with patient involvement. (box 1) (34, 35)

BOX 1

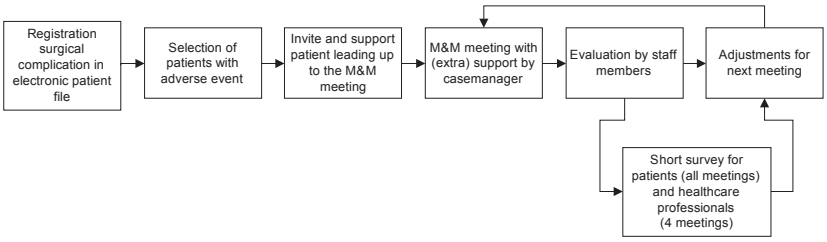
Design M&MM (before 2016)

The standard monthly M&MM was held among the gynecological team. The chief of staff selected a patient registered in the electronic patient file with perioperative and postoperative AEs marked as severe (Clavien-Dindo III-V) in consultation with, and often suggested by, the consultant.

New design M&MM: the development of the meeting structure with patient participation

The standard M&MM needed to be changed to a meeting with patient participation. A project team consisting of a gynaecological oncologist (initiator), a patient from the patient association (PAB), a case manager/nurse, a coordinator and the quality of care department developed that first design. Specific details of this new design were discussed with a hospital lawyer.

Flowchart patient participation at the M&MM and improvement cycle:



At the start of this project the selection of the first three patients was based on the patient's open mind, eagerness to be present at their M&MM, and a good relationship with the consultant, because of the inability to assess the emotional impact of the meeting. The patients that joined the following meetings were selected in a similar manner as prior to 2016. by the chief of staff in consultation with the consultant. However, the current physical and emotional state of the patient is always discussed before inviting the patient. The consultant invited the patient to join the meeting (see flowchart) and additional information was provided by their case manager on the structure of the meeting, whom to take along and answered remaining questions. All involved healthcare professionals were invited, including nurses and involved

consultants from other departments. There was no specific preparation for healthcare professionals. One of the involved surgeons, or a senior registrar, presented the case with a description, timeline, literature research and possible points for improvement. When preparing the slides it was important to use comprehensive language and a low amount of medical jargon. During the meeting the moderator (a consultant who was not involved in the AE) managed the time and clarified when necessary. The moderator initiated two specific moments during the M&MM where patients can share their experience or ask questions. Patients may also ask questions during the meeting. At the end of the M&MM there is a round where all attendees may share a final comment. The case manager assisted and supported the patient prior, during and after the meeting. In case of unresolved issues of grief, anxiety, or anger, consultation with a psychologist was offered. Both patients and healthcare professionals gave continuous feedback and answered a short survey after the first four meetings until saturation of information (see flowchart). In addition, a Steering group (consisting of the project team, patients, hospital board member, other gynaecological oncologists, registrar, ethicist, medical philosopher, lawyer) was installed to provide feedback on the design of the M&MM and current research project. When necessary, adjustments were made for the next M&MM.

Research setting

The research was carried out at the department of gynecologic oncology of a tertiary university hospital. This teaching hospital was one of the eight expertise centers in gynecologic oncology in the Netherlands, which admitted 300 new patients annually. The registered AEs classified as severe with the valid and reproducible Clavien-Dindo grading system (I-V), were discussed at the M&MMs. (36, 37) The standard M&MM was held once a month before 2016, and only members of the gynecological team such as consultants, registrars, and residents were invited.

The M&MM was held once every two months after 2016: the new design included the patient and their partner or family member, and all involved healthcare professionals from the gynecological team and other departments. Between 2016 and 2018 eleven M&MMs were organized of which eight with

patients and three M&MMs without patient participation (one of a deceased patient and two patients refused). Table 1 presents the characteristics of the eight M&MMs, patient characteristics and the belonging AEs which led to either prolonged hospital stay or readmission. Patients' age ranged between 44 and 80 years. All healthcare professionals from the gynecological oncology staff attended at least three meetings. Four consultants from other departments attended one meeting.

The study (case 2018-4713) was approved by the Ethical Review Board of the hospital (CMO Light). Written informed consent was given before the interviews began. None of the research team members had conflicting interests.

Study population and recruitment

Eight patients and 20 consultants, nurses, and registrars who participated in the M&MMs held between 2016 and 2018 were recruited in July and August of 2018 for the interviews. Each patient interview was scheduled in the privacy of the patient's own home. The healthcare professionals were interviewed in a private room in the hospital, or by phone.

Table 1. Characteristics of eight M&MM with patient participation

	Type of gyn. cancer	Procedure	Adverse event	Intervention	Time between AE and M&MM	Brought partner or family member	Attendees	Technical lessons and learning points
1	Vulvar cancer	Wide local excision with bilateral inguinal lymph node dissection	Urosepsis / wound infection	Readmission to ICU and long-term antibiotics	6 weeks	Alone	6 gynecological oncologists 2 registrars 1 fellow 1 nurse 1 senior nurse 1 case manager 1 quality department 1 coordinator	*Improvement of the antibiotic policy and wound care. *Better transfer to home care. *Provide patient with tailored alarm signals.
2	Recurrent granulosa cell tumor	Cytoreductive debulking surgery	Blood loss (7500 ml)	Multiple blood transfusion and fresh frozen plasma, 1 night admission to MCU	4 weeks	Partner	6 gynecological oncologists 1 registrar 1 nurse specialist 1 case manager 1 anesthesiologist 1 coordinator	*More focus on medication verification (listen to the patient). *Daily visits on weekends. * Patient thought the paralytic ileus was more impressive than the hemorrhage.
3	Ovarian cancer	Cytoreductive debulking surgery	Paralytic ileus	Long-term admission: gastric draining	4 weeks	Partner	5 gynecological oncologists 3 registrars 1 nurse specialist 1 case manager 1 quality department 1 coordinator	*Create a roadmap when epidural fails postoperatively.*Better explain treatment of an ileus (such as the use of gum, coca cola and the importance of movement).
4	Cervical cancer	Radical hysterectomy with pelvic lymph node dissection	Infection/ wound abscess and urethral injury	Re-implantation urethra and antibiotics	12 weeks	Alone	5 gynecological oncologists 3 registrars 1 nurse specialist 1 case manager 1 urologist 1 coordinator	*Provide clear explanation of abcess. *Patient was shocked by the wound abscess. *Patient was content with all the sincerity during her care.

5	Ovarian cancer	Cytoreductive debulking surgery	Bowel injury	Relaparotomy, partial bowel resection (ileum) with colostomy	5 to 6 weeks	Partner	5 gynecological oncologists 2 registrars 1 nurse 1 nurse specialist 1 case manager 1 urologist	*Different approach during surgery. *Better understanding of the perception of the patient.
6	Ovarian cancer	Staging procedure	Abdominal abscess	Drainage	22 weeks	Partner	4 gynecological oncologists 1 registrar 1 fellow 1 senior nurse 1 case manager 1 surgeon 1 coordinator	*Improved definition of the indication of insertion of a MESH. *Easily request for CT. *Better understanding of the domestic context.
7	Endometrial cancer	Abdominal hysterectomy, bilateral salpingo-oophorectomy, pelvic lymph node sampling	Platzbauch	Relaparotomy	8 weeks	Partner	3 gynecological oncologists 1 registrar 1 resident 1 nurse 1 case manager 1 nurse specialist 1 coordinator 1 medical anthropologist	*Preferences of suture techniques amongst colleagues. *Be mindful of the role of the partner and inform him/her on a regular basis.
8	Endometrial cancer	Total laparoscopic hysterectomy, bilateral salpingo-oophorectomy	Hematoma of the vaginal vault	Vaginal drainage and antibiotics	11 weeks (due to death in the family)	Family member	4 gynecological oncologists 3 registrars 1 case manager 1 coordinator 1 medical anthropologist	*Visual aids can support patients to understand what happened. *Better inform patients of all emergency phone numbers.

Legend:

AE: adverse event; **ICU**: Intensive Care Unit;

M&MM: morbidity and mortality meeting; **MCU**: Medium Care Unit

Data collection interviews

We used two separately developed semi-structured interview guides to interview both patients and healthcare professionals. The research team evaluated the interview guides for relevance and comprehensiveness. The interviews with patients started with open questions about their treatment, the AE, and their expectations of the M&MM. Then other topics were discussed, such as their needs and emotional processing during the meeting, information, and the effect of the relationship with their healthcare professional (table 2).

The interviews with professionals started with open questions about their experience with M&MMs, how they perceived the goal of the meeting, and their expectations. Then specific possible challenges, such as open discussions, fear of losing the patient's trust, or trust in their professional reputation, were discussed. Possible opportunities, such as the benefits of patient participation were also discussed. Both patient and professional interviews ended with a question about how they thought the meeting could be improved. A medical anthropologist, who had no previous relationship with the participants, but who had attended two M&MMs, conducted the interviews. The participants were informed about her background, degree of involvement, and the research goals

Table 2: Interview guide

General	The two interview guides were semi-structured based on (a) relevant themes from the literature on patient participation at multidisciplinary team meetings and the disclosure process of AEs and (b) practical elements of the meeting: time and timing, duration, clarity, frequency, location, and different roles of the stakeholders.
Patients	Start interview: introductory open questions to understand the experiences surrounding the treatment process and the AE. Main topics: (a) expectations and needs of the M&MM, impact and emotional processing of the AE, information, relationship with the healthcare professional, experience of the partner or family member who joined the meeting, and (b) practical elements. End interview: points of improvement for the M&MM with patient participation
Healthcare professionals	Start interview: introductory open questions about their attendance at the M&MMs and the perceived goal of the meeting. Main topics: (a) expectations of the meeting, satisfactory elements, barriers (e.g. open discussions, fear of lawsuits, losing trust and professional reputation), facilitators (e.g. benefits of patient participation) and (b) practical elements. End interview: points of improvement for the M&MM with patient participation

Legend: AE: adverse event; M&MM: morbidity and mortality meeting

Analysis

We used the Atlas.ti tool version 8 for Windows for thematic content analysis, generating codes by conventional content analysis. (38, 39) Two researchers used open coding to analyze the first two interviews, one from a patient and one from a healthcare professional. Open coding was used to allow new insights to emerge from the data with codes that were strongly connected to the transcripts. Afterwards, the codes were clustered into items, themes, and domains; partly on the basis of important topics from the literature, but derived from the data without pre-defined structures. The two researchers then coded all other interviews and adjusted the code list accordingly with the research team. This led to a coding tree. Before finalizing the coding tree, two other members of the research team, as a stakeholder of the meeting and

a methodologist, selectively coded five transcripts to detect missing topics or themes. The credibility of the data was strengthened by independent coding. A multidisciplinary research team interpreted the credibility during data analysis to select the most relevant results.

Results

Eight patients and 17 healthcare professionals participated in the study. An additional three professionals did not participate because they did not respond or believed they did not gained enough experience with attending M&MMs with patient participation. The interviews with patients lasted an average of 49.5 minutes (range 38 – 62 min). The interviews with healthcare professionals lasted an average of 30 minutes (range 20 – 44 min).

The analysis resulted in different practical constraints (see paragraph 'practical constraints') and a coding tree with eleven core themes in the interpersonal domain: three for patients, three for healthcare professionals and five shared themes relevant for both groups (table 4).

Practical constraints

The patients and healthcare professionals were enthusiastic about the practical design of the meeting, such as the duration (1 hour), the time reserved for the patient to share experiences, the presence of a strong moderator and the casemanager who tends to the patient prior, during and after the meeting. (table 3) Patients especially appreciated the personal time and attention by the casemanager.

"Afterwards, when all was discussed, everybody shook hands with me. The nurse practitioner stayed for a chat and helped me to answer a survey. I really like that."
(patient 4)

Healthcare professionals mentioned practical constraints that became apparent after experiencing several M&MMs. First, the M&MM should be organized in the morning instead of the afternoon when professionals might have outpatient clinic and are delayed. Second, the M&MM with patient participation required more preparation time that needs to be taken into account when planning an M&MM. Third, all involved healthcare professionals,

especially the external consultants, may be invited a few weeks prior to the meeting to clear their schedule. Fourth, the majority of the staff preferred the consultant, fellow, or senior registrar to present the AE. They were seen as more knowledgeable of the AE and/or could effortlessly use comprehensive language.

Table 3: Success factors of the M&MM with patient participation described by patients and healthcare professionals

Success factors
Personal attention for the patient provided by a healthcare professional (usually case manager) before, during, and after the meeting
Strong moderator: manages time, formulates the goal of the meeting, clarifies when necessary
Reserved time (within 1 hour) for patient and partner/ family member to explain their experience and join the discussion
Creation of a safe environment for healthcare professional and patient – discuss in a respectful way with equality (without professional hierarchy)
Meeting planned within 3 months after the AE or medical error
A well-structured format or guideline in order to translate learning points (from the meeting) to practice change
Professionals familiar to the patient (and the patient's case) should attend the meeting
Patient is well informed about the goal of the meeting: organized for medical professionals to learn from preceding events, where the patient can share their story and join the discussion
A presenter who focuses on comprehensive language and is aware of the "painful" aspects
The meeting is in a room with U-shaped seating: the patient is seated close to the presenter and next to the case manager or the consultant

Legend: AE: adverse event; M&MM: morbidity and mortality meeting

Interpersonal dynamics

The thematic content analysis resulted in a coding tree with eleven core themes related to interpersonal dynamics (table 4).

Table 4. Code tree and quotes from patients and healthcare professionals

PATIENT	
Trust and safety	"That they create an overview and yes that is very nice. That is such a feeling of trust that everything will be all right. And then you have 100, no 200 percent of trust in them." (patient 4)
Information	"Some things were explained briefly [after the AE], it was explained very well again the next day … and during the meeting. When that happens, you have nothing to complain about." (patient 7)
Active involvement	"If I can contribute something that will provide someone else with better treatment, or something similar, I would like to be involved in that." (patient 3)
HEALTHCARE PROFESSIONAL	
Notions of quality	"I think the goal of the M&MM needs to be the priority, what you want to achieve. And, what could the patient add to that." (consultant 5)
Patient-centered attitude	"I can remember a meeting ... where the discussion was quite strong and then I thought these things would have been discussed if the patient wasn't there as well. … So I looked at the patient and her partner every now and then, to see whether they handled the information well, and they did." (nurse specialist 1)
Balance for the patient	"We should be careful the meeting will not be a performance or summary for the patient, but that it keeps covering the content: ... what happened, how we solved it, whether it was good or whether it could have been better. And the medical focus remains." (registrar 2)
SHARED THEMES	
Doctor–patient relationship	"So I think it is really important you have a relationship based on trust, as a healthcare professional, with the patient that joins the M&MM, that she [the patient] feels at ease. (external consultant, urologist 13)
Open communication	"...but make sure that you check regularly whether the patient understands you. …and don't be afraid to show how it is written in literature, protocols or what we know from other research."(resident 3)
Language	"All the medical jargon is explained of course. And yes, it was all very clear. It was also clearly indicated that if you don't understand what is being said, you can ask for clarification. Then everything will be all right." (patient 8)
Learning	"Seeing the AE through the eyes of the patient provides more and different learning points" (fellow 12)
Personal Impact	"If you as the consultant personally advise a certain treatment [and an AE occurs]. Then you do feel very vulnerable as a consultant." (consultant 5)

Legend: AE: adverse event; M&MM: morbidity and mortality meeting

Patients

Trust and Safety
Patients experienced a bond of trust with their consultant and the casemanager, and explained that in effect they also trusted other healthcare professionals; "*I felt complete trust in all those doctors*" (patient, 4). This trust resulted in feeling safe to share experiences, ask questions, and feel comfortable during the meeting.

Information
Every patient was curious and expressed a need to have all the information about the passing events surrounding the AE. This was important for some patients who forgot aspects of the treatment process, due to the anaesthetics, pain, or stress from their personal situation.

"We wanted to see what happened, because we experienced a lot of stress and therefore we have missed some information and what exactly happened." (patient 8)

Active involvement
Upon invitation patients agreed to join the M&MM without hesitation, no matter the age or type of AE. The most important reason was to actively contribute to improving healthcare for future patients by sharing their own experience. Patients also wanted to understand how healthcare professionals deal with AE and what they learn from them. This way, patients explained, they could understand better why something did not go as planned and found acceptance in what happened.

Healthcare professionals

Notions of quality
Healthcare professionals described different notions of quality of the meeting but everybody mentioned maintaining "the quality" of the meeting as important. These notions were related to ideas about the content of the learning points, the type of discussion, and the role of the patient.

Describing learning points that are relevant for clinical practice seemed to be a way to achieve quality of the meeting. In order to achieve that, an open

discussion was considered a measure of quality of the meeting that has to give room to "*bring everything to the table*" and "*be frank*".

"I think that the greatest danger or defect is that in that situation the discussion would not be held at its sharpest, which might eventually lead to a point where you would not discuss certain points of improvement."
(registrar, 3)

Professionals experienced some limitations to openness in the discussion, mostly during the first three to four M&MMs, as a way to reach what they perceived as quality. After experiencing several meetings with patient involvement, healthcare professionals felt more free to express themselves more openly and comfortably:

"*In the beginning you carefully try what works well in the conversation with patients,…but you do notice that it is easier after a while.*"
(consultant 5)

Professionals expressed that the content of the meeting was improved. Due to (1) input from the patient and their partner or family member, (2) input from other disciplines, (3) the experience of the professionals in communicating about difficult situations and (4) a well prepared presentation.

Patient-centred attitude
During the M&MM healthcare professionals described they acted attentive to the experience of the patient, such as by observing the patient and to see how they reacted. The consultants and the moderator often verified with the patient whether they had any other questions. The moderator also summarized parts of the discussion. In addition, the professionals expressed they were interested in the patient's perspective and experience of the AE.

Balance for the patient
Professionals explained they felt like they had to balance between hosting a medically oriented M&MM, or a patient focused M&MM. This was related to the balance between the use of medical jargon and lay language and the time reserved for the patient. During the first meetings some professionals were concerned that the patient would not understand the meeting and the

information might harm them, which led to simplistic language and too much focus on the patient instead of the learning aspects. However, after feedback of patients and family a better balance in medical but understandable language was used and a better focus on learning points improved. These aspects remain challenging but, especially with more experience, these challenges do not seem to negatively influence the focus or goal of the meeting.

Shared themes

Patient–doctor relationship

Both professionals and patients said that a patient–doctor relationship with open communication was the foundation for a meeting where both stakeholders feel comfortable in sharing their experiences and actions. Healthcare professionals mentioned feeling less vulnerable when this relationship was stable. In this relationship it was important for patients to be acknowledged in how they experienced the AE, which gave them a feeling of being treated as an equal. This also reflected in patients feeling heard and taken serious during the M&MM. All patients appreciated the time healthcare professionals took during the meeting to listen to their experiences.

" I just really appreciated how you [the department] do it now. Be transparent, clear, and honest. That gives you a feeling of… being important. …That things are discussed in this manner and that you are taken seriously, in your whole story."
(patient, 8)

Communication openness

The most valued part of a stable relationship for both patients and professionals was transparency of information. Seven of the eight patients did not hear new information related to their AE during the M&MM, which aligned with their sense of trust and expectations that healthcare professionals had been open and honest during the process of consultation and treatment. Healthcare professionals mentioned open communication between colleagues and the patient, as a condition in order to host M&MMs with patients. External consultants, for whom this was the only opportunity to discuss the AE, experienced this as more difficult. The staff of the department of gynecological oncology was described by them as capable of being open

about the AE, however, they were most impressed by the openness of the patient.

"At first I thought how can I speak freely during the meeting but it makes a difference that they [the patient] were very accessible and open."
(external consultant, 17)

Transparent communication was experienced by patients and professionals as a reason why patients did not feel a need to receive an apology or file a law suit, and healthcare professionals were not afraid of a law suit as a result of the M&MM. However, some professionals assumed that in cases of severe AE, or patients with strong negative emotions, it would be more challenging to communicate openly.

Language
Healthcare professionals wanted to provide patients with an opportunity to be involved in the discussion. However, they were concerned whether the patient would understand everything and if the (technical) medical topics in the discussion would get enough attention.

"…That is what we consultants do. Speak in diminutives when we want to make it simpler and not too heavy. …we should be careful that that does not happen, so it remains an adult and worthwhile meeting."
(consultant, 5)

However, the experience of healthcare professionals changed over time because they felt more comfortable to discuss medical topics with the presence of the patient. Patients were eager to join the M&MM, were positive about the amount of information and clarification during the M&MM, and did not experience the (technical) medical language as negatively affecting their experience of the M&MM. In addition, patients accepted the fact that some parts would be difficult to understand and focused on other elements that were important to them.

Personal impact
Patients felt supported in their emotional and mental processing of the AE. Even though the meeting was experienced as exhausting on a mental and

emotional level, it helped several patients find closure after a difficult period. Even so, healthcare professionals feared, or assumed, that medical and open language about severe events may influence patients' well-being. In some M&MMs healthcare professionals explained they felt more vulnerable, especially if they felt personally responsible for the AE.

"If you as the consultant personally advise a certain treatment [and an AE occurs]. Then you do feel very vulnerable as a consultant."
(consultant 5)

Learning

At the start of the M&MM the moderator mentioned the meeting was installed to learn from passing events and ultimately to improve healthcare. At the end of each M&MM a report was written with the learning- and action points relevant for clinical practice. However, it was not always clear for the professionals whether the learning points that resulted from the meeting were acted upon in (clinical) practice.

Healthcare professionals described they gained new perspectives at the end of the meeting from the fact that the discussion was held with a multidisciplinary team of professionals and the presence of the patient (table 1). Hearing about the patients' experience created a better understanding of the effect of the AE on the patient. Professionals explained the level of (technical) learning as depending on the type of AE and whether the patient felt comfortable to share their experience. One example that multiple healthcare professionals gave during the interviews were the learning points from meeting 3 (see table 1). A nurse gave the patient chewing gum and Coca Cola to drink, which supports the recovery of an ileus. The patient did not take these items because the nurse did not explain the rationale of using these and the patient did not like them. Therefore, the main learning point came from the experience of the patient: certain information may need to be explained further and as medical professionals we must reflect on how we communicate to the patient.

In return, patients gained a better understanding of how professionals work together between teams, which, as they explained, changed their perspective on the future care they will receive from that same hospital. The partner of

a patient explained he acknowledged the fact that healthcare professionals have to learn as well.

"And everybody can make a mistake.... If a mistake is made, then you can learn from it. That is also true."
(partner of patient, 6)

Discussion and Conclusion

Discussion

This is the first study about patients participating in their own M&MM. This research resulted in different themes and elements for the practice of M&MM that are important for patients and healthcare professionals. The most important conditions for organizing such an M&MM where both patients and professionals feel safe to share is a supportive patient–doctor relationship whose principle feature is openness. This condition led to a setting where the patient felt safe sharing their story and asking questions, and where healthcare professionals could discuss more freely after attending several M&MMs. However, a balanced use of lay and medical language and reaching an open discussion were challenging. Most of the practical elements of this first design should be maintained. These elements include the support from a case manager or nurse before, during, and after the meeting, a strong moderator, and repeated invitations to all involved healthcare professionals.

This research adds to the literature about patient participation in medical meetings due to its unique context. (23, 25, 40-42) Partnership is seen as an important process that supports participation and as part of realising patient-centered care. (43, 44) Studies also describe equality as an important component of patient participation. (45) Within this study patients felt taken serious and heard, which provides testimonial justice for patients even though varying relations of power still exist. (46) When patients feel taken serious, a sense of equality is experienced and a partnership can be realised. However, that sense of equality seems to have certain conditions, such as the patients' emotional state and openness of communication from both sides. (9) Other research encountered concerns from healthcare professionals for the involvement of patients, such as the patient's ability to cope with the

information discussed and whether the dynamics in the meeting would change. (40, 41) The fact that patients in our study embraced their new role during the M&MM is an important factor in achieving participation. (8) Another study showed comparable results where healthcare professionals were challenged when adjusting the medical jargon and discussing openly with the patient present. (23) Our results show that healthcare professionals felt more comfortable, after attending several meetings, to discuss all aspects of the AE with the patient. Therefore, participation in this context seems to be a process that creates opportunities for a new culture of openness when professionals discuss and learn from AE.

One of the main goals of M&MMs is to learn from the meeting. In order to learn effectively, the learning environment needs to be safe and supportive; open communication should be possible. This is partly related to the constant interaction between attendees and the impact people can have on each other during critical discussions. (47) This study showed that aspects of healthcare communication can be part of the discussion during an M&MM with multidisciplinary healthcare professionals and patients as attendees. (48-51) A positive experience of the M&MMs gave professionals the incentive to be more open during discussions and open to learn in each meeting. Patient participation can therefore be viewed as a learning intervention. Some studies found that most learning points of M&MMs focused on "individual and technical performance", and neglected other areas of improvement that involve collaboration with other disciplines, or at a systems level. (52, 53) Although learning points from the meeting are important for improving current clinical practice, the report itself was hardly read and professionals were unaware whether the learning points lead to practice change. However, the fact that professionals explained that they learned from the perspective of the patient, may indicate that professionals learned more, perhaps unconsciously, than solely the learning points that were written down in the report.

The strengths of our study are the multi-disciplinary research team providing complementary input. In addition, all the patients that joined an M&MM and the majority of the healthcare professionals were willing to participate in the interviews. A limitation of the study is the fact that eight patients and the majority of the 17 healthcare professionals participated in different

meetings. They might have had a different exposure as to how the meeting was executed.

Although this study shows a design that leads to positive patient experiences in the M&MMs, the challenge to implement the learning points from the meeting to change clinical practice remains, and more research is needed in this field. (20, 53) In addition, further research is needed whether patient involvement negatively impacts the learning process and openness of the discussion in specific situations/ cases. An important focus for future development of the meeting needs to concentrate on providing a safe space for all attendees to have in-depth, honest discussions and the time to inform and prepare the attendees. Furthermore, research is needed in other surgical departments with different types of patients and AEs to understand the contextual factors related to its execution and further the development of its design. (54)

Conclusion

Participation of patients in their own M&MM while experiencing trust and safety is possible when there is a stable patient–doctor relationship, a balanced use of medical and lay language and a support system provided by the involved healthcare professionals. Patients and the involved healthcare professionals valued the practical aspects of this M&MM design. Patient participation is possible when professionals are open to discuss and to learn from the AE with patients present. In this setting patients feel taken seriously and gain a better understanding of the course of the AE.

Practice implications

Both patients and healthcare professionals are positively surprised about a joint M&MM where AEs are discussed. Involving patients at the M&MM leads to new insights, better understanding, and improved processing of the AE. However, it is challenging how to balance a medically oriented discussion that leads to learning points, while communicating in comprehensive language. Developing a healthcare innovation with patients' feedback seems to be effective in the current setting. Our blueprint of the practical organization of the meeting may be used in other (surgical) departments.

Acknowledgements

The authors would like to thank all the patients who participated in the morbidity and mortality meetings and the research, and they would like to thank the healthcare professionals who participated in the research.

Funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Ethics approval

The study (case 2018-4713) was approved by the Ethical Review Board of the hospital (CMO Light).

I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

Data availability statement

Data are available on reasonable request.

Competing interests statement

None declared.

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chapter 4

Involvement via video-conference

Patient involvement via videoconference at the morbidity and mortality (M&M) meeting during COVID-19

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BMJ Open Quality 2022; Feb 11(1): e001691.
doi:10.1136/bmjoq-2021- 001691.

keywords
Patient participation; COVID-19; morbidity and mortality rounds; telemedicine

Introduction

The development of online meetings and innovative online patient and public involvement (PPI) increased in the last decade, but the COVID-19 pandemic pushed healthcare delivery towards remote solutions more rapidly. (1) This may be seen as a logistical, technical, as well as a cultural shift. (2)

Due to the COVID-19 pandemic, online programs and tools have been developed to guide healthcare professionals in setting up video consultations. (3) Healthcare professionals may benefit from requiring knowledge and skills of digital technology, ethics of online communication and specific communication competences. (4) Barriers may arise for patients with unfamiliarity with the technology used (often elderly patients), low hearing or vision, or patients that require more emotional support. (5)

COVID-19 also influenced our morbidity and mortality (M&M) meeting at the department of gynaecology, which we organize with patient participation since 2016. (6) Involving patients at their M&M meeting is a form of PPI. During these meetings with the patient (and relatives), adverse events (AE) are discussed with professionals in order to learn from what happened to eventually improve healthcare. (7, 8) Due to COVID-19 safety regulations, patients were invited to join the M&M meeting online instead of in-person. The aim of the study is to evaluate online involvement of patients at M&M meetings to understand the most important supportive and challenging factors. The outcome of previous research on in-person patient involvement at M&M meetings is used to understand the similarities and differences with online involvement. (6)

Methods

Setting

The department of gynaecology organized monthly M&M meetings that discussed the AE of one patient. The M&M meetings in this pilotstudy followed the same design as in-person patient involvement. (6) The main adjustment was including the safe videoconference tool 'Lifesize'. (9) This tool required the patient to enter a code and password from home. Patients

received a step-by-step plan with instructions to test the tool prior to the meeting. Each meeting was studied prospectively.

Data collection

Experiences of patients and professionals attending M&M meetings via Lifesize were evaluated by semi-structured interviews and observations (fieldnotes). Professionals who experienced both patient participation in-person, as well as online were invited for an interview. The interview guide for patients focused on their current experience of a M&M meeting and their experience with 'Lifesize'; the guide for professionals focused on the similarities and differences between in-person and online patient involvement. We received ethics approval (2018-4713) and informed consent was obtained from each patient prior to participation. Data saturation was reached after five M&M meetings. Interviews were conducted via telephone, recorded and transcribed by BM, and lasted between 10:38 and 29:26 minutes. Fieldnotes were written by BM. Written informed consent and permission were obtained. Data were stored in a folder with a digital key.

In total five M&M meetings were included in the study. Five patients and eight healthcare professionals participated in the interviews (one consultant, four registrars, one casemanager (nurse), one nurse specialist, one coordinator/ nurse-researcher). Professionals attended one or several M&M meetings. Patients' ages ranged between 25 and 55 years. The AEs ranged from mild to severe complications, and included: hemorrhage after cervical leep excision (LLETZ), abdominal abcess, hemorrhage after laparoscopic cystectomy of dermoid cyst, inaccurate diagnosis after biopsy that led to a more invasive procedure than proved necessary after final histology, leakage of a colorectal anastomosis.

Data analysis

Atlas.ti version 8.4.20 was used for thematic content analysis of the transcripts of the fieldnotes and the interviews by two researchers (BM, PZ). (10) After reading all transcripts open coding was used to descriptively label each phrase or sentence. Similar codes were clustered into subthemes and discussed upon agreement. These subthemes were merged into the five themes that resulted from the evaluation study of in-person patient involvement. (6) Subsequently, if subthemes did not fit in the established thematic framework they were

clustered separately and discussed until consensus was reached (BM, JdH, JK, RH, PZ).

Results

Our findings show that all five themes significant for both patients and professionals attending a M&M meeting with in-person patient involvement remained relevant in an online setting: a balanced use of comprehensible language; an established patient-doctor relationship; open communication; personal impact of an AE; and we found comparable medical/technical learning points as well as learning points in the field of communication and collaboration. The relevant themes for online patient involvement were nonverbal communication and experience with a videoconference tool. Table 1 shows an overview of the themes similar to in-person M&M meetings, and the themes specific for online patient involvement.

Table 1. Themes arising from online patient involvement at morbidity and mortality meetings

Themes	Similar to in-person patient involvement*	Specific for online patient involvement
Language	x	
Patient-doctor relationship	x	
Open communication	x	
Personal impact	x	
Learning	x	
Nonverbal communication		x
Experience with videoconference tool		x

*Myren et al. 2020

Due to a lack of nonverbal communication in an online setting professionals experienced that it was difficult to grasp whether patients understood everything and how it impacted them. Additionally, it required extra attention for clear formulations, to speak slowly, provide regular summaries and to invite the patient to respond. Patients experience the latter as helpful and felt taken seriously. One patient specifically mentioned that a more personal question from a consultant showed that they took an interest in her experience. The question concerned whether the patient would have chosen differently if she would have known back then what she knows now. "I think people should

always ask these type of questions. That you should be genuinely interested in what the effect is on a patient when something like that happens." (patient 1) Patients felt well prepared to use the videoconference tool and knew what to expect from the online meeting. Both professionals and patients mentioned that as a result of COVID-19 they were more used to and/or comfortable with using videoconferencing tools.

Professionals with experience of in-person patient attendance would prefer the latter, in order to have a better understanding of patients' nonverbal language. Yet, all interviewees were satisfied and professionals experienced the patient as a valuable addition. Our learning points of online patient involvement at the M&M meetings were to have a videoconference system that patients can use easily, that has the option for a second person to login during the meeting (companion of the patient), and to facilitate a setting where especially the patient is clearly visible in order to see as much nonverbal communication as possible. In addition, the goal and structure of the M&M meeting has to be clear for all attendees in order to have an organized meeting and to prevent miscommunication. Table 2 provides a summary of the collected data, clustered in three categories: practical advice, supportive factors and challenging factors of online M&M meetings.

Table 2. Practical advice and supportive and challenging factors

Practical advice	Organize high quality image and sound in the meeting room
	Use a room with 2 screens: one for the presentation and one for the videoconference
	Organize a user-friendly videoconference tool and provide clear instructions for both professionals and patients
	A partner or family member of the patient can join with the possibility to log on from a different device
	During meeting: welcome the patient first and introduce all attendees
	All attendees are visible
	Frequent summaries during the meeting are helpful
	Actively ask the patient to share their experiences and comments
	Speak slowly with a loud and clear voice
	Do not interrupt speakers
Supportive factors	Prior to the meeting: the patient receives clear explanation of the structure and goal of the meeting
	The video conference tool is tested with the patient prior to the meeting
	Healthcare professionals have experience with the conference tool used
	Patients do not have travelling time which makes it easier to plan into their daily program
	Casemanager or attending consultant calls patient afterwards (on the same day)
Challenging factors	Some patients may be unfamiliar with videoconference tools
	Facilities used for Lifesize meetings may not be in order and functioning properly
	Nonverbal language is more difficult to observe
	There is only 1 camera facing the meeting room: the patient sees professionals on a small scale and it may be difficult to see who is talking

Discussion

The online M&M meeting was implemented rapidly and successfully during COVID-19. Although professionals experienced some limitations, the benefits of patient participation remains the same as for in-person involvement. (6) The experiences of in-person patient involvement were positive for both patients and healthcare professionals.

Although comparable learning points resulted from the online meeting, to better understand the patient's experience professionals may need to develop a skillset that includes e.g. awareness of the patient's tone of voice and facial expressions. (11-13) Less eye contact may make users feel uncomfortable or disconnected by a lack of social presence. (14, 15) Yet, patients in our research did not express feeling uncomfortable or disconnected. Perhaps, due to the preparation, the attendance of familiar faces and the time reserved for patients before, during and after the meeting including emotional support. (16, 17) Moreover, it is likely that some patients felt comfortable because they gained experience with videoconference tools for personal or work-related use.

Openness to patient participation and experience with live attendance is important to achieve an inclusive M&M meeting, also to manage changes towards a digital work environment. (5, 18) Our department will keep inviting patients to their M&M meeting post-COVID-19 to attend either in-person or via Lifesize.

Acknowledgements
We would like to thank all patients and healthcare professionals for their time to participate in the research.

Ethical approval
The study (case 2018-4713) was waved by the Ethical Review Board Arnhem-Nijmegen (CMO Light).

Competing Interests
None declared.

Funding
None declared

Data availability statement
Data available upon request.

Patient and public involvement
Patients were previously involved together with the department of process improvement and innovation; patients were involved in the design, conduct, and dissemination plans of research on patient involvement at the morbidity and mortality meetings, as well as part of the steering group.

Patient consent for publication
Not required.

Contributorship statement (CRediT)
BM: B.J. Myren, MSc., Conceptualization, Methodology, Software, Formal analysis, Investigation, Data Curation, Writing - Original Draft, Writing - Review & Editing, Visualization, Project administration; JH: J.A. De Hullu, MD, PhD, Conceptualization, Formal analysis, Validation, Investigation, Resources, Writing - Review & Editing; JK: J.J. Koksma, PhD, Conceptualization, Methodology, Validation, Formal analysis, Data Curation, Writing - Review & Editing; RH: R.P.M.G. Hermens, PhD, Conceptualization, Validation, Methodology, Investigation, Formal analysis, Resources, Writing - Review & Editing; PZ: P.L.M. Zusterzeel MD, PhD, Conceptualization, Validation, Investigation, Formal analysis, Resources, Data Curation, Writing - Review & Editing, Supervision.

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chapter 5

improve implementation

Cyclic workflow to improve implementation of learning points from morbidity and mortality meetings

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BMC Health Services Research 2022; 22, 1282.
doi:10.1186/s12913-022-08639-2.

ABSTRACT

background
Morbidity and mortality meetings (M&MMs) are organized in most hospital departments with an educational purpose to learn from adverse events (AEs) to improve patient care. M&MMs often lack effectiveness due to unsuccessful systematic follow-up of areas of improvement. This can have an effect on improving patient safety and care. Therefore, a new strategy that focuses on implementing areas of improvement into daily practice is necessary. The study aim is to see if we could improve the implementation of meeting outcomes from the M&MM by using a cyclic workflow, and which factors are important to achieve its implementation.

methods
This prospective study took place at the department of gynecologic oncology of a university hospital. Research was conducted with a participatory action research (PAR) approach using 10 consecutive M&MMs in 2019 and 2020. The cyclical workflow consisted of an action list based on the PDCA-cycle, a check of the implementation of areas for improvement at the next M&MM and regular monitoring of tasks. Each M&MM was observed and each professional with an assigned task was interviewed and gave their informed consent. Thematic content analysis was performed with the program Atlas.ti 8.4.20.

results
Out of the 39 tasks that resulted from 10 M&MMs, 37 (94.8%) followed all the steps in the PDCA-cycle and were implemented. In total, 16 interviews were conducted with consultants, nurses, registrars and residents. Five main factors were important to achieve follow-up of areas for improvement: organizational culture, motivation, commitment, communication to mobilize employees and skills. Repetition of the cyclic workflow at the M&MM and an external person who reminded professionals of their assigned task(s) was important to change habits and motivate professionals.

conclusions
Cyclical tools can support the implementation of areas for improvement to optimize the M&MM. A M&MM with an organizational culture where attendees can discuss openly and freely may motivate attendees to take on tasks successfully. A positive stimulant to reach commitment of professionals is team participation. Integrating new habits of reflection may lead to a deeper level of learning from the PDCA-cycle and of the M&MM. Creating a learning environment outside of the M&MM may support professionals to take on actions and engage in improvement practices. Future research may focus on including a comparative analysis to show a success rate of the implementation of learning points from the M&MM more clearly.

keywords
healthcare quality; organizational change; group meeting; patient participation; workflow; learning; complications.

Introduction

Morbidity and mortality meetings (M&MMs) are important to improve patient safety and surgical quality of care.(1, 2) Having an effect on medical practice is in particular important for M&MMs, which are organized in most hospital departments with an educational purpose to learn from adverse events (AEs) to improve patient care.(3, 4) However, although areas for improvement result from the M&MM, the desired expectation of practice change or systematic follow-up of areas for improvement lack effectiveness.(5-9) The learning points resulting from the M&MM are not succesfully implemented in daily practice. In order to improve the methods of the M&MM and support the implementation of areas for improvement in daily practice, professionals need to change their routine behavior.(10) Therefore, an improvement strategy that strengthens the systematic follow-up of areas for improvement may need to focus on active engagement of professionals.(11)

Next to the engagement of professionals, research outlines strategies for effective meetings with tangible results.(12-14) These include, having routine items, such as closing the meeting with a clear delegation of follow-up points and using an agenda with recurring actions.(12-15) A popular cyclical workflow that includes both elements, is the Plan-Do-Check-Act (PDCA)-cycle. This PDCA-cycle is a method to continuously improve quality of processes. It systematically follows the process of making a time-based improvement plan, recognizing and analyzing problems, to finally follow the steps leading to improvement in practice.(16) Even though this workflow contributes to a cycle of learning that includes elements of reflexivity (17, 18), more research is needed to understand the effectiveness and sustainability of the PDCA-cycle.(19, 20) Quality improvement should itself be viewed as a learning process for professionals and the organization.(21) Therefore, the PDCA-cycle may function as a way to optimize the working environment as a learning environment by increasing the frequency of reflecting and acting by professionals.(22) The follow-up of areas for improvement from the M&MM may depend on the professional's attitude towards including these tasks in practice. Moreover, behavioral change is key to support the successful uptake of an improvement strategy which requires learning processes.(23, 24) Therefore a work environment, or organization, should stimulate that type of learning. Especially in a healthcare context where professionals have

routine behavior and set ways of working. Although there are few examples of successful implementation of the PDCA-cycle at M&MMs, this has not become common practice in most hospital departments.(25)

In 2016 the department of Gynecologic oncology of an academic Dutch hospital in the Netherlands successfully implemented patient participation at the M&MM as standard care. (7, 26-27) Our research, as well as other studies, showed that patient participation at similar meetings result in different and new perspectives and improves the meeting. (7, 26, 28-30) For example, well prepared meetings because it created an additional urgency to provide evidence based arguments and new insights in comprehensible language for the patient, and diverse learning points in the field of collaboration and communication. In our department the professionals experienced commitment to communicate a written report of the status of the meeting outcomes to the patient after three months. However, learning points from the M&MM were not always implemented in practice and specific practical tools to record and enable healthcare professionals to engage with the follow-up of meeting outcomes were lacking. Therefore, we needed a strategy that focuses on systematic follow-up of areas for improvement from the M&MM with patient participation. Practical tools were developed with elements of the PDCA-cycle in order to include a cyclic workflow. Due to the importance of changing professionals' routine behavior, this study also focuses on factors that may explain the underlying processes that positively or negatively affect the implementation of a cyclic workflow. This can be studied by observing closely what works and what does not, and by encouraging participants to take action.(31, 32) These processes should be better understood to provide generalizable advice on the level of organizational culture, motivational drivers and group interaction at the M&MM.(33)

The aim of this prospective study was to improve the implementation of meeting outcomes from the M&MM by using a cyclic workflow, and which factors are important to achieve its implementation.

Material and methods

Research setting & improvement strategy

The research took place at the monthly M&MMs at the department of gynecology of a university hospital in the Netherlands . Figure 1 outlines improvement strategies part I & II implemented to improve the M&MM since 2016. The first improvement strategy patient participation changed the meeting structure by inviting all the involved participants.(3) The goal of the traditional M&MM did not change with patient participation: one AE is discussed with the aim to learn from what happened and to improve practice. However, some adjustments were made: professionals used comprehensive language, the goal of the meeting was explained prior to every meeting, and all attendees were introduced to the patient (and companion). The patient was invited to bring a companion, such as their partner, a family member or a close friend who could also share their experience. During the M&MM the patient (and companion) had time to share their experience, provide feedback and join the discussion. The chair was an independent consultant from the department, experienced in chairing M&MMs. The presentation was conducted by a fellow or senior registrar involved in the case, supervised by the consultant. Regular attendees were the patient and a companion, gynecological consultants, registrars, residents, research nurse and casemanager from the department. Occasionally consultants from other departments (anesthesiology, surgery, urology, etc.) and nurses from the ward attended as well, depending on the case.

The second improvement strategy cyclical workflow was developed in 2019, and included PDCA-cycles. The practical tools were co-designed with healthcare professionals familiar with common barriers of implementing areas for improvement into daily practice, members of the hospital emergency management committee and the executive researcher (BM). The tools of the cyclical workflow were based on existing PDCA tools used by the hospital emergency management committee and current practice of the M&MM. These included an action list based on the PDCA-cycle (table 1), personal contact (BM) to follow-up on the tasks after two weeks, one month and 3 months (when necessary); Reserving the last 15 minutes for reflecting on tasks from the previous meeting(s) was a new structured item of each M&MM with patient participation. Successfully executed tasks followed all the steps in the PDCA-cycle as shown in table 1 and were implemented accordingly.

Figure 1: Elements of improvement strategy part I and II implemented between 2016 and 2020

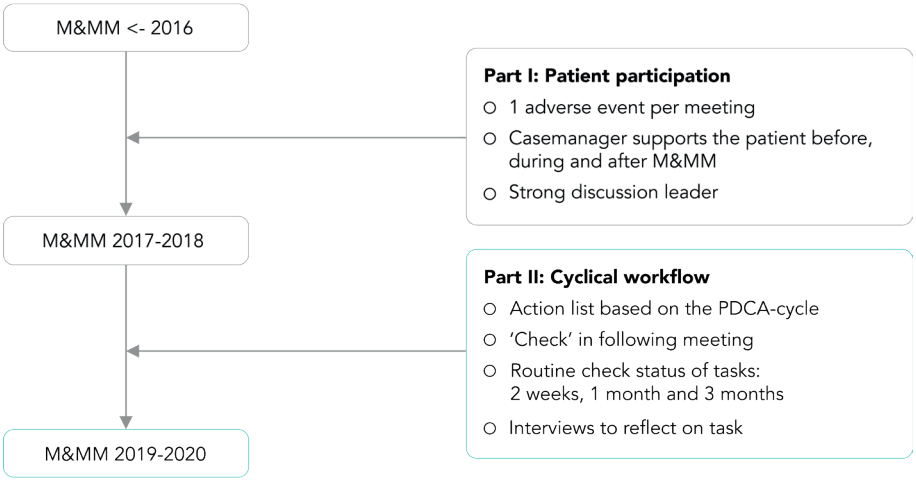


Table 1: Primary columns of the action list based on the PDCA-cycle

			PLAN		DO		CHECK	ACT
Nr	Outcome of M&MM	Professional with assigned action (name/ function)	Desired result (goal setting)	Steps to achieve goal setting	*Start date improve-ment activity*	*Desired date to finish improve-ment activity*	Check whether action is completed (date /how)	Additional measures and/ or actions

Research design

Participatory Action Research (PAR) & participants

Qualitative research methods were used to evaluate the factors involving the successful implementation of the practical tools to understand 'what works, why and under which circumstances'.(34) Participatory action research (PAR) is a methodology that can involve the researcher as a participant in the research context to collect data.(34) In our study the researcher attended each M&MM, created each action list and communicated with healthcare professionals on the status of their tasks. This way the PAR approach stimulated an exchange between the participants in the study and the executive researcher.(35-36) It provided opportunities for continuous attention to observe and recognize patterns of behavior over time.(36-38) In addition, interim results of the study were shared during the implementation of the cyclical workflow with research team members who attended the M&MM, while collecting data.

Data collection

Qualitative data was collected from 10 M&MMs with patient participation in the period of 2019-2020.

Interviews

Semi structured interviews were held in Dutch by the executive female researcher (BM) with all professionals who were assigned to a task on the action list. The researcher was familiar with professionals who attended the M&MM regularly. One of the inclusion criteria to participate in the research was to have a task assigned at the end of the M&MM. Professionals were invited to join the research via e-mail. In total, 16 interviews were conducted with consultants, nurses, registrars and residents and lasted between 12 minutes and 32 minutes. The open interview questions focused on practicalities, possible difficulties in finalizing the task and why it was (un)successful. In addition, the interviews inquired about the impact of using the practical tools implemented at the M&MM, their motivation to finish the task, whether they shared the outcomes with their colleagues and whether it impacted their view on patient-centered care. All interviews were held via telephone, recorded and transcribed verbatim.

Observations

Each consecutive M&MM was observed by the executive researcher (BM). These observations focused on the formulation of action points during the meeting, whether attendees took on tasks and the division of tasks. A task was successfully executed when the professional finalized and implemented each step of the PDCA-cycle described on the action list. The researcher used fieldnotes during the observations, which were extensively written down after each M&MM. E-mails that involved actions were also included as data.

Data analysis

The transcribed interviews were analyzed in the program Atlas.ti (version 8.4.20, Atlas.ti Scientific Software Development GmbH; Berlin, Germany) by two coders (BM, MG). The content analysis method and elements of narrative analysis were used, such as coding larger blocks of text to better take the professionals' full story into account.(39) In the first round, both coders used open coding in three different transcripts. Based on these codes different broad categories were clustered. In the second round the transcripts from the first round were coded again with three additional transcripts. After each round both coders discussed the categories to detect missing topics, or the relationship between the categories. The coders discussed upon agreement with quotes or parts of the transcripts to support the arguments. The authors (PZ, RH, JH, JK) provided feedback on the code tree and came to agreement in a meeting before the third round of coding started. In the third round the other transcripts were coded and the theoretical perspective from literature was added to define the themes found in the content analysis. The observations were used to contextualize the interview transcripts during the analysis of the interviews and to detect behavioral changes. A rating of importance was given to the factors. This was based on both interviews and observational data that showed which of the factors eventually led to following all the steps in the PDCA-cycle and successful implementation.

Ethical considerations

All methods were carried out in accordance with relevant guidelines and regulations under Ethics approval and consent to participate. This research was approved by the local Medical Ethical Committee of the hospital ('CMO Regio Arnhem-Nijmegen') case 2020-6142. Prior to the interview professionals received information concerning the research, gave their informed consent

and knew the researcher was involved in different research focusing on improving the M&MM. The attendees were made aware of the presence of a researcher observing during the M&MMs. The interview recordings were deleted after transferring them to a computer with folders protected by a digital key. The COREQ checklist was used during the research to adhere to criteria for reporting qualitative research.(40)

Results

We found that improvement strategy cyclic workflow aids in the follow-up of areas for improvement at M&MMs based on the analysis of 10 meetings. Five main factors were important in the uptake and implementation of tasks. In the following section we present six successfully implemented PDCA-cycles, and the five factors that are important for the implementation of the improvement strategy.

Actions and successful examples

The 10 M&MMs resulted in action lists with 2 to 5 actions per meeting. 37 of the 39 tasks (94.8%) followed all the steps in the PDCA-cycle and were implemented. Each task was assigned to a professional. Additional steps were described and added to the action list in the last column when the tasks were checked, usually at the following M&MM. Two out of the 39 tasks were not finalized or completed. These tasks were assigned to professionals from a different, external department and included follow up of research on a procedure. Paragraph 3.2.2 explains that it took more time and attention to motivate professionals from external departments to finalize tasks. Table 2 shows six successfully finalized tasks with a description of the AE that was discussed during the M&MM.

Table 2. The action list tool with six successfully implemented tasks

Adverse event (AE)	Outcome of the morbidity and mortality meeting (M&MM)	PLAN: Desired result (goal setting)	Steps to achieve goal setting	CHECK/ ACT: Check whether goal is achieved and whether additional steps are needed
2020, January Haemorrhage (blood loss> 500ml) after leep excision	Insufficient knowledge about hemostasis material in colposcopy room.	Inventory of (available) options for haemostatic material (websearch) after a leep excision.	Liquid silver nitrate and Surgicel© as standard absorbable hemostats in the colposcopy room. All team members are aware of which materials are present and where it's stored in the colposcopy room.	Lecture held on absorbable hemostats. Liquid silver nitrate is no longer available.
2020, February Recurrent urinary tract infection due to urinary retentions after removing the bladder catheter too soon following a Wertheim-Meigs procedure.	Make bladder scans after Wertheim-Meigs procedure when catheter is removed as urine retention occurs more often. If necessary, longterm catheter à demeure, self-catherization are options.	Standard of care protocol used in the ward which bladder retentions are acceptable after a procedure (in this case Wertheim-Meigs procedure).	Healthcare professional assigned to the action will check and modify the protocol if necessary.	There is a standard protocol at the inpatient department after surgical procedures of urology, surgery and gynaecology. Protocol does not need to be modified. Additional action: Everyone is aware of this hospital wide protocol.
2020a, June Wound dehiscence ("space belly").	The suture used for closing the fascia was too short. Two sutures were tied together, leading to a weak spot.	Based on new advice - long PDS barrel (300 cm) is ordered.	Order long PDS barrel.	The PDS barrel is ordered and since July 2020 both short PDS barrel (120cm) and long barrel (300cm) are available.

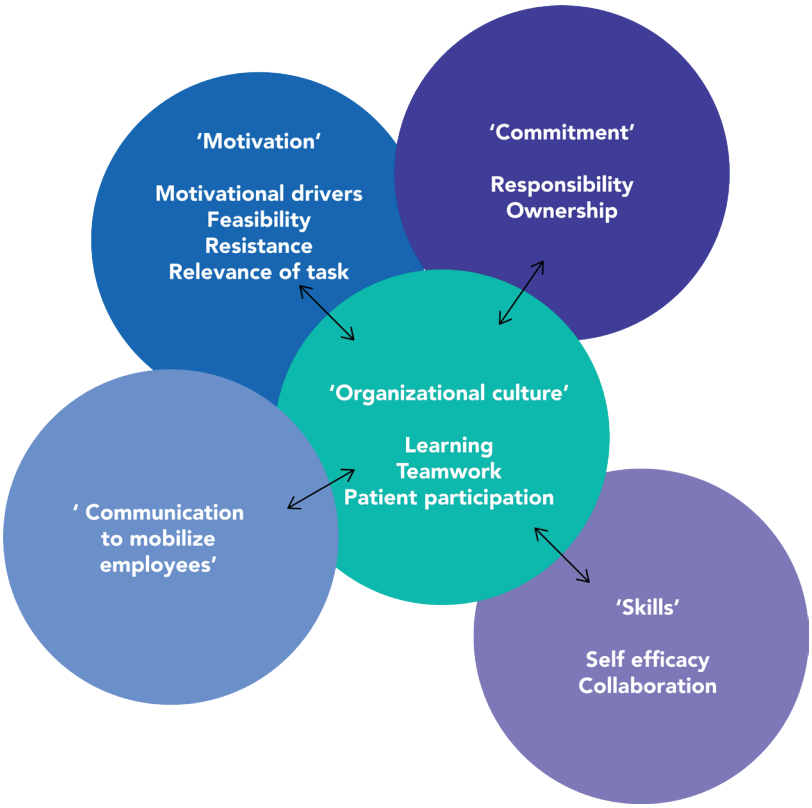
Adverse event (AE)	Outcome of the morbidity and mortality meeting (M&MM)	PLAN: Desired result (goal setting)	Steps to achieve goal setting	CHECK/ ACT: Check whether goal is achieved and whether additional steps are needed
2020, July Excessive CO2 accumulation during a laparoscopic procedure.	Clear communication during surgery about peri-operative issues between anesthesiology team and operative team. In patients with higher BMI, the use of longer trocars is necessary to prevent CO2 leakage subperitoneal.	Also record complications with respect to anesthesia. If necessary, introduce additional time-out during OR in case of impending complications. Order longer trocars.	Repeat the outcome at the following M&M meeting. Order longer trocars. Create awareness of the risk of CO2 accumulation during surgery.	Actions are accomplished, and discussed again at the following meeting.
2020, August Overbalanced liquid intake postoperatively.	The liquid balance was not documented.	During each bedside rounds the liquid balance is documented (input and output within a 24-hour period in millimeters).	Organize education on liquid balance for registrars and at the inpatient ward (C5). State liquid balance in the electronic patient file at every bedside round.	Additional education for registrars and nurses on the overbalanced liquid intake policy postoperatively took place.
2020, September Wound infection.	High risk of infection after inguinal wound. Particularly in patients with adiposity. Research other agents that may aid in wound repair.	Start flushing the wound postoperatively with povidone iodine solution. Communicate with infection prevention/ hospital hygienist to determine how to reduce the risk of wound infection with these procedures. -> Evaluate the outcome of the use of povidone iodine solution in wound infections after 6 months.	Each staff member will record in the OR report if the wound was flushed postoperatively. Schedule appointment with hospital hygienist.	Each staff member is aware that whether or not the wound was flushed with povidone iodine solution needs to be stated in the patient's operating report. Contact has been made with hospital hygienist at a later stage (Due to COVID-19 this was postponed). After 6 months the use of povidone iodine solution was evaluated (data from operating reports).

Relevant factors for successful implementation of areas for improvement

Analysis showed five main factors explaining underlying reasons of why professionals included their assigned task in their routine behavior: organizational culture, motivation, communication to mobilize employees, commitment and skills (see figure 2). The most important factor was organizational culture that influenced the four other factors. Motivation was the second most important factor that influenced three other factors. All professionals who received a task at the M&MM accepted the invitation to join the research and were interviewed.

Figure 2 shows the five main factors and sub themes. These five factors will be illustrated by a successfully executed task from table 2: 'overbalanced liquid intake postoperatively'.

Figure 2: Five factors relevant for the successful implementation of the improvement strategy



Organizational culture

Professionals explained a supportive culture as an environment where; outcomes were discussed openly without judgement, they can admit to mistakes and receive support when a task was not yet successfully finalized. For example, at the M&MM concerning the overbalanced liquid intake postoperatively there was an open discussion that led to a clear division of tasks (see table 2, case number 5.). The nursing staff as well as a consultant together with a registrar who did not attend the M&MM, were assigned with a task. In general, the implementation of areas for improvement was effective when professionals could easily collaborate with colleagues, when there was a clear division of work-tasks and when professionals could use their own creativity to finalize the task. The latter was especially important when the task was not part of the daily responsibilities of the professional. The action list and the continuous communication with the researcher were accepted quickly by participants because experienced professionals responsible for the M&MM introduced the improvement strategy. Professionals explained in the interviews that the culture at the M&MM, and outside of the M&MM, provided an environment that supported behavior change and also motivated professionals to actively engage with their task.

'For me it is no problem to say hey guys maybe I did not do this in the right way. … Because when you discuss this with people [colleagues] they will support you and look into it to see what it is you did.'
(#8, registrar gynaecological oncology)

Motivation

In the example of the overbalanced liquid intake postoperatively, nurses were motivated because they were aware of the importance of their task, they felt responsible and were capable of executing the task. The registrar who did not attend the M&MM was not motivated at first. Although it was the registrar's responsibility to organize monthly education, this caused resistance as she only received a short e-mail, was unaware of the AE and unfamiliar with the case of that patient.

In general, motivation was explained by the motivational drivers of professionals (reasons why professionals feel motivated), when a task on the action list was feasible, when the action suited the professional's role and

responsibilities and when it was seen as relevant (see table 3). Moreover, when an action suited the professional's role, the professional felt a sense of ownership that enhanced their motivation. Professionals experienced resistance when they did not feel taken seriously, did not have enough knowledge about the AE, or when they were not present at the M&MM. The visibility of practice change by sharing the result of a succesfully executed task was an important motivational driver for most professionals. Therefore, the action list needed to be shared with the team and stored in an accessible location.

'Look, everything that can improve the quality of care, that is something we should do. And that should be disseminated as well. Because there are also people who say 'I did not hear about it afterwards and what is the situation right now'. Then you can say what we agreed upon is here on the drive and this was sent around.'
(#6, consultant gynaecological oncology)

External factors could positively or negatively influence the motivation of professionals. Professionals explained that they became more motivated when the researcher used e-correspondence to check the feasibility and status of the task prior to the following M&MM. This was especially important for professionals from other departments, because they did not attend the following M&MM where tasks were checked and reflected upon. The additional personal contact was crucial at the start of the intervention, because professionals needed to get acquainted with, and reminded of, their assigned task on the action list.

Table 3. Overview of motivational drivers, resistance and general advise for underlying reasons of (un)successful use of the improvement strategy

Motivational driver	Resistance found during research	General advise
A sense of ownership	• Professionals who were not present during the M&MM and received an action afterwards • Professional who were made responsible for an action without giving consent	• Explain the assigned action via phone call or an explanatory email • Explain clearly when an action is part of someone's role and responsibilities
Clear action description with deadline and an environment that promotes independency	• Unclear action/ not feasible • Professionals who lacked the skill to be creative and autonomous in finishing actions • The person who described the actions on the action list lacked the skill to do this consistently and clearly	Describe the action SMART [Specific, Measurable, Achievable, Realistic, Time-related)
A sense of urgency and relevancy of the action	Professionals who received too many emails; emails may be overseen	Repeat actions in other (weekly) meetings
Visibility of the status of the actions	Professionals who did not see or find the status of the action, and/or the action is unclearly written	• Make the action list available on a shared location • Provide regular (short) updates by e-mail with the status of the actions
Multidisciplinary M&MM with new perspectives and inter-departmental support to execute actions	Professionals from other departments did not feel motivated to finalize the action	• Organize regular M&MMs with other departments • Create extra contact moments with professionals from other departments about their actions • Make someone from your own department responsible for the finalization of an action by another department
Visibility of practice change when actions are executed	It was unclear whether the action influenced or changed daily clinical practice	Share action with colleagues and invite colleagues to support in completing the action
Improvement of the quality of care (described as a feeling)	Professionals who received an action that was unrelated to their daily responsibilities or work-role	The actions should fit and align with the daily work-role of the person with an action assignment

Communication to mobilize employees

In the example of the overbalanced liquid intake postoperatively, nurses received an e-mail by the executive research (BM) with an informal and relatable tone. These nurses attended the M&MM and were aware of the AE and its consequences. They were also able to mobilize their colleagues and inform them about the policy changes (their task). The registrar did not attend the M&MM and therefore needed to receive a different way of communicating her assigned task.

'So I think you should assign tasks to people who are part of the group of attendees. And then the task will be to mail person x [person who did not attend the meeting], and the one who receives the task is person y [person who attended the meeting]'.
(#10, registrar obstetrics)

This could also have been a phone call with additional information or a more elaborate e-mail. Receiving a task, or checking for the status of that task, required a tone of mutual respect especially when a professionals was unable to attend the M&MM. In general, communication about the content of the task was important to mobilize professionals to actively engage with their task. During the improvement strategy the communication about the tasks occurred during the M&MM when areas for improvement were formulated, and in outside of the M&MMs by the researcher. This was only possible when the overall (hierarchical) culture provided space for another person (here: researcher) to assign tasks.

'Yes, well I have seen your name more often so I know what you do related to your research and so on. So I did not think it was weird that this questions came from you. No, definitely not.'
(#12, nurse gynaecological oncology)

In addition, it is important to have experience in how to clearly formulate and write tasks on the action list. We found that writing down tasks clear for all professionals required a specific skillset that includes medical knowledge. The executive researcher lacked medical knowledge and was therefore unable to describe some tasks.

Commitment

Our results showed that commitment went beyond motivation. This meant that a committed professional was always motivated to finalize his/her action. Both the nurses and the registrar were committed to finalize the task because it was part of their regular work description. Most professionals explained that they felt a sense of ownership and ultimate responsibility of the task, regardless whether they had enough time to follow-up on it.

'Yes, but either way, even when there is no problem, I feel ownership… So even when the task would have been assigned to someone else and it does not make sense. Even then, it could be possible that this person thinks I am responsible.'
(#11, consultant gynaecological oncology)

Due to the importance of commitment, the professional that takes on similar tasks in their daily work needed to be assigned to the task despite their full schedule. In order to make sure that a specific professional takes on this task, it required a professional, next to the researcher, knowledgeable of the different roles and responsibilities of each member in the team of professionals.

Skills

In general, self-efficacy was explained by a culture that stimulated professionals to start immediately on their task, plan necessary activities, be creative in finding solutions to execute the task and propose follow-up actions. In the example of the overbalanced liquid intake postoperatively, both the nurses and the registrar were able to finalize their task and collaborate. They planned the necessary activities to change the liquid balance policy and used their own creativity to organize the education. The organizational culture in the team may have supported them in using these skills.

'Most of the time my colleagues in gynaecology respond well to my feedback. Ofcourse, with a degree of exceptions.'
(#13, senior registrar gynaecological oncology)

Overall the action list supported professionals in their self-efficacy, because this provided a clear overview of tasks and deadlines. Professionals who were aware of the knowledge, network and daily work-tasks of other colleagues were better equipped to collaborate and execute the task on time.

'With these types of protocols, each nurse in our department has a specific focus such as pain, palliative care, or wound care. So first we need to meet with them to see what the protocol entails, whether everything is clear to them, how they ensure people use the protocol and whether they need to do something with the protocol related to the M&MM, or whether it was just an incident.'
(#6, consultant gynaecological oncology)

Discussion

Areas for improvement resulting from the M&MM with patient participation can be successfully implemented into daily practice supported by a cyclic workflow and motivated professionals to take on and finalize tasks. Our study showed that 37 tasks (94.8%), of a total 39 tasks from 10 M&MMs, followed the PDCA-cycle and were successfully implemented. Five factors described the underlying reasons for the behavior of professionals while carrying out assigned tasks: organizational culture, motivation, communication to mobilize employees, commitment and skills.

We found that almost 95% of the tasks followed the PDCA-cycle and were implemented. This may indicate that the meetings were effective and the cyclic workflow created opportunities for successful meeting management in the context of M&MMs that include patient participation.(41-42) Research focusing on M&MM characteristics and the implementation of actions for improvement shows that the depth of analysis of the AE, including a focused discussion, is a key issue for effectiveness.(43) Although this may indicate that the discussion and analysis of the AE in our M&MMs were thorough, we may still question whether and what professionals actually learned. What constitutes learning for professionals may impact how the tasks assigned to them are valued and addressed to in the future. Perhaps professionals required deeper learning to make the PDCA-cycle effective and to integrate learning whilst executing tasks in their professional way of working. This means that in addition to learning how to follow the PDCA-cycle and finalize tasks, professionals may also connect learning from the M&MM to a normative level of what constitutes good care and leadership. The PDSA-cycle may be more suited to facilitate learning while implementing tasks from the M&MM.(44) It is important to not only create functional meetings, but facilitate reflective practices that lead to transform current practice.(45) This may facilitate more

diverse discussions about the implications of areas for improvement for patient care and collaboration. When implementing this cyclical workflow in other settings this may be taken into account.

The success of a PDCA-cycle, which is a set framework, often lies in the adaptation to the local context and an iterative processes that may inform the next cycle. In our study several areas for improvement concerned topics discussed in previous cycles, such as wound infections. Therefore, several cycles iteratively informed other cycles and enabled one of the key features of a PDCA-cycle which is documentation.(20) Professionals in our study appreciated documentation, because it showed the steps that were taken to improve clinical practice and reached the goal of the M&MM which is learning from AEs. The reminders and repetitive contact may have stimulated professionals to act differently during implementation of the cyclic workflow. Even though literature shows that repetition may establish new habits, continuous reflection is preferred within a learning environment.(46, 47) The study approach of participatory action research (PAR) revealed that reflection, facilitated during interviews, was important for professionals to describe why their task was important and that they wanted to improve the quality of care. The time reserved to reflect on the actions in each of the following M&MMs contributed to the learning environment as well. However, as indicated in our study we advise to formulate tasks clearly and SMART (Specific, Measurable, Achievable, Realistic, Time-related). Moreover, it is important to additionally integrate new habits of reflection in the work setting outside of the M&MM. (36,44)

The five factors that resulted from the research show that the social environment can positively or negatively stimulate behavior during the implementation of the cyclic workflow. A sense of commitment and support from the environment seemed to facilitate the successful execution of tasks. The tools based on the PDCA-cycle supported professionals by offering clarity, structure and a possibility to check tasks in the following meeting. We found that organizational culture seemed to have a strong influence on the successful implementation of our improvement strategy. Culture is a complex construct and general strategies to change and improve healthcare culture are lacking.(48-49) However, our study showed that commitment of professionals is an important factor while improving the follow-up of areas

for improvement. This translates to a motivated professional which in effect can support changes in healthcare culture. In our study an external person stimulated professionals to follow-up on tasks. Although this may be related to a busy schedule of professionals that required reminders, it may also have been a way to motivate professionals to take on tasks.(50) This shows that there is a role for management or professionals in leading positions to facilitate a healthcare culture where attendees of the M&MM are motivated to implement tasks. Moreover, management may also take on facilitating a strong organizational structure around M&MMs that includes coordinating team members to improve the M&MM with a cyclical workflow. Overall, the implementation of a cyclic workflow required a committed professional to use the tools at the M&MM and to implement their assigned task.

Organizational commitment is defined as a force that ties an individual to work towards relevant targets.(51) When a group of professionals (employees, managers) experience commitment to an improvement strategy it may play a role in the successful implementation as it reduces resistance to organizational change.(52) Organizations with committed employees are more effective. When organizations wish to increase a sense of commitment in professionals it is important to create an environment that stimulates behavior to work on specific tasks and facilitate participation in teams.(53-55) A sense of participating in a team will be more clearly felt when attendees speak openly and freely without shame or blame during the M&MM. This can support the commitment of attendees in taking on tasks as a team effort. Although in some countries there might be a fear of legal or negative repercussions when AEs are openly discussed, M&MMs with patient participation at our department did not lead to more complaints or any form of litigation by patients.(56)

A strength of this study is the PAR approach that stimulated interaction with the researcher and the participants during the implementation of the cyclic workflow. This resulted in detecting and implementing necessary adjustments of the M&MM. The multidisciplinary research team provided diverse input during data collection and analysis. A comparative analysis of the follow-up of areas for improvement prior to the improvement strategies was not available. Therefore, this study could only establish the effectivity of the current improvement strategy based on the extent to which professionals followed-up on the PDCA-cycle and implemented the tasks. This research

faced a limited and context specific setting in which the research is conducted. A possible bias is that the executive research was familiar with several professionals who received a task. Although putting an external person in charge of sending reminders may be a limitation to the sustainability in the current study context, we suggest that a coordinator who supports in the organization of M&MMs may function in this role external to the core team of professionals. Future research may include a comparative analysis to show the success rate of the implementation of learning points from the M&MM. Future research on success factors of implementing learning points from the M&MM may also benefit from using theoretical frameworks such as the Consolidated Framework for Implementation Research (CFIR) and the Theoretical Domains Framework (TDF) to investigate behavior change during implementation.(57, 58)

Conclusion

In conclusion, an improvement strategy with a cyclic workflow and regular communication supports professionals at the M&MM to actively engage with their tasks and eventually improve clinical practice. It remains important to motivate professionals by putting an external person in charge of sending reminders, creating the right (learning) environment in- and outside of the M&MM to change behavior and sustain the uptake of the tools.

Ethics approval and consent to participate

All methods were carried out in accordance with the Declaration of Helsinki and regulations under Ethics approval and consent to participate. The study was approved by the Ethical Review Board Arnhem-Nijmegen of the hospital (CMO Light) case 2020-6142. Prior to the interview professionals received information concerning the research and gave their informed consent.

Content for publication

Not applicable.

Availability of data and materials

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests

Funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Authors' contributions

Conception (BM,JH,JK,MG,RH,PZ); research design (BM,JH,JK,RH,PZ); research analysis (BM,MG,PZ); interpretation of data (BM,JH,JK,MG,RH,PZ); data curation (BM,MG); writing – review and editing (BM,JH,JK,MG,RH,PZ); supervision (JH,JK,RH,PZ). All authors read and approved the final manuscript.

Acknowledgments

The authors would like to thank all the patients and healthcare professionals who participated in the morbidity and mortality meetings and the research.

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chapter 6

transformative learning

Patient participation at the morbidity and mortality meeting: a transformative learning experience

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Social Science and Medicine - Qualitative Research In Health 2022;Dec 2:100105.
doi:10.1016/j.ssmqr.2022.100105.

ABSTRACT

purpose

Implementing a patient-centered innovation is a complex process that requires commitment and attention from the healthcare professionals and organizations involved. Even though studies show how patient participation can be achieved in clinical care, it has hardly been studied as a learning process. This study aims to understand a patient-centered innovation as a potentially transformative experience.

method

The study included morbidity and mortality meetings with patient participation (M&MM-P) at the department of gynecological oncology over a five year time period (2016-2021). Data was collected by action research methods including ethnography, in-depth- and semi-structured interviews, various observations and attendance lists, and secondary analysis of transcripts. Data was analyzed with thematic content analysis (Atlas.ti 8.4.20).

results

The results include 17 M&MM-Ps, interviews with eight patients, 17 healthcare professionals, nine observations and two attendance lists of M&MM-Ps. In total 56 healthcare professionals participated in M&MM-Ps. Patient-centered innovation may bring about transformative learning when professionals gained a lot of experience. Three overarching clusters emerged 1) feelings of trust and relatedness, 2) convictions about what constitutes good care and practice improvement, and 3) underlying perspectives and frames of reference.

conclusions

Prolonged, repeated experience with M&MM-P resulted in changes in behaviors and perceptions of healthcare professionals about person-centered care and patient participation. These experiences became potentially transformative when healthcare professionals were open and willing to push the boundaries of their professional identity, could critically reflect on their normative ideas about 'quality of care', and welcomed workplace learning as a form of care improvement complementary to more straightforward ideas about implementation.

keywords

Patient participation; patient-centered care; morbidity and mortality meeting; quality of care; healthcare innovation; workplace learning; perspective taking; transformative learning

Introduction

The current paradigm in health care quality improvement does not always align with the dynamic, contingent and personal nature of daily practice. Grounding quality of care on a particular type of scientific evidence has helped healthcare enormously over the past decades. However, the evidence-based medicine (EBM) movement currently faces criticism that much EBM research is 'wasteful' by overlooking the broader patient perspective. (1-3) Nevertheless, there is an ongoing need for useful scientific evidence that clinical practice and patients will benefit from. (4) Science should help advance practice as a learning environment open to various ways of knowing and contrasting perspectives. (5, 6) Quality institutions and researchers list patient-centeredness among the criteria for good quality of care (7), but in a puzzling juxtaposition to other items, like care having to be efficient, timely and effective. This does not shed much light on how quality should come about when a patient and a doctor meet.

Nowadays, patient participation is considered key to quality improvement, showing positive effects on treatment adherence and dialogue between patient and professional.(8, 9) For such effects to occur, participation needs to comprise sufficient levels of equality, partnership and ownership in decision-making processes, as well as commitment from healthcare professionals and organizations. (10-13) Patient participation seems to facilitate change in behavior, daily care, policy and interventions. (14-16) Ever since the report To Err is Human by the Institute of Medicine (IOM) in 1999 there has been an increasing attention for research on quality improvement strategies in the field of patient safety. (17) This report not only provided insights in the shocking number of adverse events (AE), but also increased awareness of the importance of human behavior in building a safer health system. This report pointed towards a lack of full disclosure of AEs to patients, and a lack of openness and transparency amongst healthcare professionals. Involving patients in safety may be seen as a crucial step because the patient is the only constant factor during all steps in their treatment. (18) Moreover, the patient provides a unique perspective on the causes of adverse events such as in the field of communication and collaboration. (19) However, challenges arise when patients participate in healthcare improvement due

to the hierarchical healthcare system with power imbalances. For instance, patient experiences are often not evaluated or patients may be formally but not genuinely included in the process ('tokenism'). (10, 20) This raises the question whether such improvement efforts actually lead to better care and increased patient-centeredness, and how this should be determined. (21-25)

Over time, implementation science has become a separate field for improving quality of care. (26) Research on patient participation in this field shows benefits, but it still largely acts within an input-output reasoning paradigm. It scarcely acknowledges patient participation as a form of healthcare innovation in itself, and undervalues how the very process may enrich the perspectives of people working within healthcare. (27-29) Studying these social innovations demands capacities like bringing together different views and interests. (30) The learning sciences can provide new ways of looking at quality of care and help organizations improve innovation as a learning process. (31-33) The field of workplace learning perceives the whole workplace as a learning environment, providing opportunities to perceive work dynamics, such as patient-centered care, as learning ground. However, learning is often perceived by professionals as something external to their jobs, associated rather with explicit educational settings like continuing medical education (CME) or continuing professional development (CPD). In spite of this perception, people in a workplace setting learn constantly - informally - through experience. Consciously or unconsciously, they are socialized by their environment. Changing workplaces offers possibilities for people to transform their thoughts and behavior by experiencing what is not known. (34) Thus, studying workplace learning in an innovative patient-centered context may yield useful insights into healthcare improvement. Even when innovations are seen as learning journeys towards increased quality of care, the workplace becomes a more meaningful learning environment already. (6)

To study changing perspectives in a workplace-based setting, we looked at patient participation at morbidity and mortality meetings (M&MMs) as a learning process. M&MMs are traditionally organized to discuss adverse events (AE). They also have an educational purpose, to learn from what happened and improve healthcare. (35) M&MMs focus mostly on technical learning points related to daily clinical practice. There is evidence that supports the benefits of patient involvement in M&MMs, including the ability of patients

to provide new perspectives on the causes of AE, increased openness after AEs and an overall positive experience among patients and healthcare professionals at multidisciplinary team meetings. (36-39) Workplace learning in a patient-centered context is a relatively new field, and new in the context of M&MMs. (40, 41) Patient participation in M&MMs (M&MM-P) may fuel different kinds of learning processes and frame reflection that go beyond the technical areas of daily practice.

The core beliefs of participants in an innovation may influence their ability to achieve active learning. Healthcare professionals are trained to think and work in a certain way that shapes their belief systems, the majority of their undergraduate years even in the absence of real patients. (42) These beliefs encompass normative convictions and core values of healthcare delivery, and determine how they professionals perceive themselves or how they should act professionally. (43) An innovation that impacts daily routine or work habits, may challenge those long-held beliefs. New experiences can lead healthcare professionals to accept new ways of working, but also create resistance. (34) Hence, healthcare professionals' frame of reference may affect the way patients are involved. It may generate doubts about how much responsibility patients should have, how much information they can handle, and whether it is 'safe' for professionals to be open and honest. (44) Patients also have their own long-held beliefs about healthcare and how they would like to be treated. Changing these frames of reference, such as how professionals feel about patient involvement in a clinical setting, is a transformative learning process, that depends on awareness and developing and maintaining a reflective attitude. (44-46) This change in their workplace is tangible and will most likely challenge the healthcare professionals in terms of their work methods, emotional capability or communication with the patient. The aim of this study is to understand the patient-centered innovation M&MM-P as a potentially transformative experience.

Methods

Setting and approach

The research took place at the department of gynecological oncology at a tertiary hospital in the Netherlands. This department takes on around 300 new

cases with gynecological cancer annually. The research team consisted of a medical anthropologist (executive researcher), two gynecological oncologists (who simultaneously attended M&MM-P) and two social scientists in the field of healthcare innovation and improvement, and in transformative learning.
In this setting we analyzed the innovation process of the M&MM-P over the course of five years, and scrutinized transitions in their way of working and changes in perspectives or core beliefs.

Intervention M&MM-P

Together with a patient, case manager and the quality department of the hospital, a gynecological oncologist from the department initiated and developed the new M&MM format with patient participation (M&MM-P). (47) It was the patient who initially came up with the idea, when asking whether she could be present at the meeting where her case would be discussed.
Since the start of M&MM-P in 2016, several aspects were adjusted over time to create a suitable atmosphere for patients to participate. During the pilot period in 2016 (n=4), consultants were mindful of inviting patients to the M&MM-P that were willing and able to communicate during such a meeting, and with whom they formed a positive relationship. After the pilot each AE that had learning potential for the team was discussed with the patient at M&MM-P. At each M&MM-P the consultants from the department of gynecological oncology (the staff) were invited, and all the involved healthcare professionals of that particular AE (nurse, casemanager, registrar, and consultants from other departments). The duration (one hour) and frequency (once a month) did not change. The most significant changes were: the use of comprehensible language instead of solely medical jargon; a strong moderator who focused on time management; a clearly prepared presentation; support for the patient prior, during and after M&MM-P by a case manager.

While observing at M&MM-Ps, the researcher remained at the back of the room. The two gynecological oncologists, who simultaneously attended M&MM-Ps but did not present cases, were able to distinguish between their perspectives as an attendee and a researcher. They provided an insider's view on the reality of the culture of discussing AEs at M&MM-Ps (emic perspective) in addition to the outsider's view of the other researchers in the team (etic perspective). They therefore provided clarifications (at research meetings and

during data-analysis) of the behavior and specific communication between healthcare professionals. (48)

Research participants

The participants in this study were selected by criterion sampling: all attendees of the M&MM-P between 2016 and 2021 were included in the research. (49) These were patients and their partners or family members (companion), consultants, registrars, residents, and nurses. Occasional M&MMs without patient involvement were excluded from this study. The AEs ranged from mild to severe complications, and included: hemorrhage after cervical leep excision (LLETZ), Urosepsis and wound infection, blood loss (7500 ml), abdominal abcess, inaccurate diagnosis after biopsy that led to a more invasive procedure than proved necessary after final histology, hematoma of the vaginal vault and overbalanced liquid intake postoperatively.

Data collection: qualitative research methods

Action research methods including ethnography and in-depth interviews were used to understand the underlying learning processes. The action research methods involved the researcher as part of the organization; and research team members who also attended M&MM-P as consultants of the team. This study included previously collected transcripts from in-depth- and semi-structured interviews and observations as part of an evaluation study by Myren et al. (2020). (47) Additional observational data and attendance lists were included and collected between 2018 and 2021.

Interview data

The transcripts of the interviews collected in the study by Myren et al. (2020) were M&MM-P 1 to 8 (2016-2018). The interviews with patients (and their companion) were conducted in the privacy of their homes, the interviews with healthcare professionals were conducted in a private room in the hospital. Interviews were conducted using a guideline focused on their experiences and practical constraints with attending M&MM-Ps. Transcripts were suited for secondary analysis with a learning perspective due to elaborate descriptions of their experiences including opinions on M&MM-P in 2016-2018.

Observational data

The observations were collected over a period of two years 2018-2020 to

observe a process over time. In total, observational data was gathered from nine meetings (nine hours), e-mails, small talk, and discussions or remarks during research meetings. The observations were focused on a learning perspective, guided by the themes that resulted from the study Myren et al. (2020). In order to observe change, each observation focused on attitude, opinions and perspectives on M&MM-P. The executive researcher observed without participating in the discussions during the meetings. The researcher was involved with organizational tasks, such as sending out invitations. The observations were not recorded, but written down in fieldnotes during the meeting and further elaborated on and extensively recorded afterwards. Additional attendance lists were gathered to observe the frequency professionals attended.

While observing, the executive researcher started to familiarize herself with the gynecological oncology staff, so as to be better able to distinguish their medical attitudes and personality traits. Consequently, the fieldnotes could better describe differences in tone of voice and inter-collegial dynamics. However, it remained important for the executive researcher to cross check observations with members of the research team.

Data analysis

Secondary analysis was performed on both the transcribed interviews and fieldnotes of the observations from a learning perspective. (50, 51) Together the transcribed interviews and observational data were analyzed using a grounded research approach. With regards to the learning perspective, we focused on elements such as change of perspective, opinions, reflection, different types of behavior and changes in language, or behavior. These observations were crucial to understand changes over time. For this analysis we used an 'evolved' grounded theory genre where we began with open coding and then used axial coding to identify missing central themes. (52) After re-naming the main themes of the code-tree from our previous research, we performed selective coding to detect missing themes or phenomena. These outcomes were first discussed in inter-coder meetings with a clinician from our research team. Two coders then furthered the analysis of missing themes and discussed upon agreement. The researcher BM who observed all the M&MM-Ps provided context during the discussions in each phase. Finally, after careful consideration and multiple discussions, the various themes were

categorized into three main clusters. The thematic content analysis was performed using the program Atlas.ti version 8.4.20.

Ethical considerations and reflexivity

The study was approved by the Ethical Review Board of the hospital (CMO Light Arnhem-Nijmegen; case 2018-4713). All interviewees received a letter and signed the informed consent form. At each meeting the moderator clearly introduced the executive researcher in her role as an observer and explained the goal of the research.

All the interview and observational data were saved in a private location with a digital key accessible to the main researcher and principle investigator. The transcribed interviews were anonymized. Other researchers involved in the data analysis did not attend the M&MM-Ps, thus protecting the privacy of the studied population.

Results

In total, 17 M&MM-P were included in the study. Attendees from eight M&MM-P were interviewed consisting of eight patients and 17 healthcare professionals (consultants of the department of gynecological oncology, consultants from other departments, registrars, nurses); and general and specific observations from nine M&MM-Ps. An overview of the 17 M&MM-Ps and the type of collected data per meeting is shown in table 1.

Table 1. Overview of different types of collected data

M&MM-P	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
Interviews patients (n=8/17)*	x	x	x	x	x	x	x	x									
Interviews professionals (n=17/56)	x	x	x	x	x	x	x	x									
Observations (n=9/17)							x	x	x	x	x	x	x	x	x		
List of attendees (n=2/17)																x	x

* and partner/ family member

Legend: The 25 interviews and observations (7-8) from M&MM-P 1-8 were collected in Myren et al. (2020).

First, we will outline the frequency with which professionals attended an M&MM-P, showing patterns of repetition for different professionals. Second, we will elaborate on the code tree development based on the interviews and observations resulting in three clusters of ten emerging themes.

Patterns of experience over time and related to professional background

Depicted below are the attendance per department (Figure 1) and development of experience of attendees participating in a particular M&MM-P over time (17 meetings between 2016-2021, Figure 2). Of the 56 healthcare professionals in total that participated in the 17 M&MM-Ps, a large majority attended only once (61%), or once or twice (79%). Almost half of this group included members of other departments that joined an M&MM-P when invited for a specific AE. The other half were registrars with a temporary internship at the department of gynecological oncology. A specific group of healthcare professionals from the department of gynecological oncology (18%) (square in Figure 1 with different professions) obtained a higher number of experiences (attending 4-18 times).

Figure 1: Number of times professionals attended an M&MM-P per department

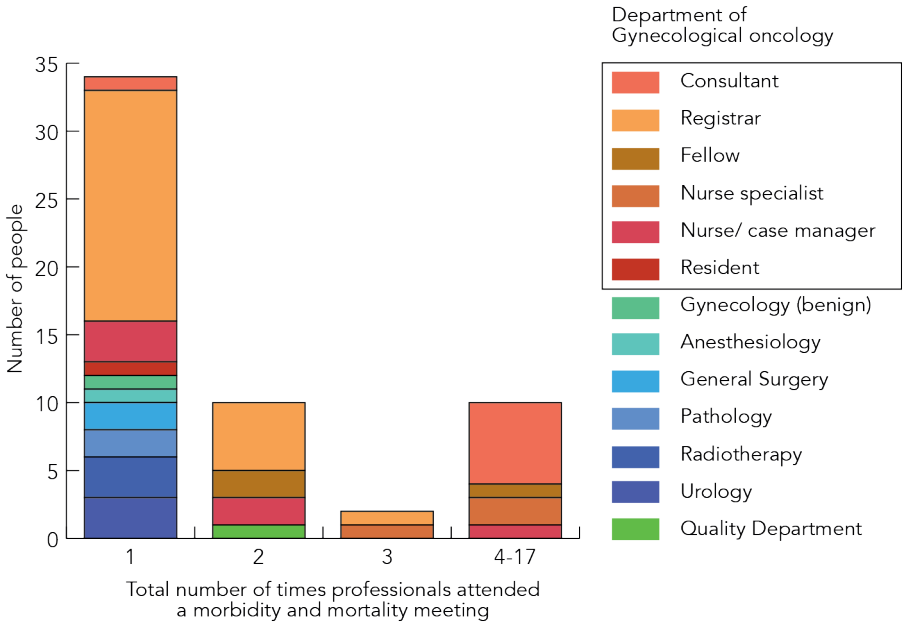
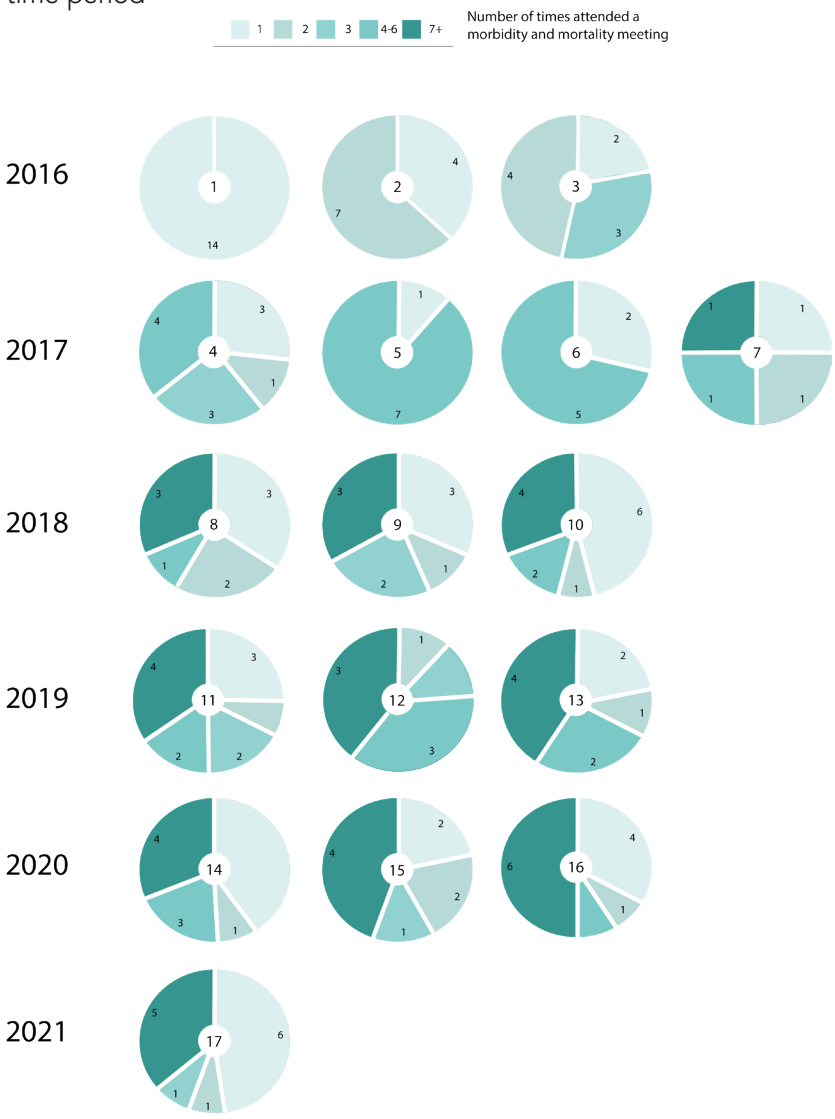


Figure 2 shows an overview of the experience of the attendees for each of the 17 M&MM-Ps over a five year time period. Over the course of 2016 and 2017 the group of initiators gained more experience. From 2018 onwards the group of new attendees grew and the M&MM-P group makeup started to settle on a pattern with a one to one ratio between experienced and non-experienced attendees. As such, the M&MM-P learning environment underwent a focus shift from the initiators' learning processes towards those of the less experienced attendees. This also became visible during the observations, with the experienced group setting the tone and pace, and often stimulating or directing the discussion towards different (sensitive) topics. As the interviews were conducted with professionals with a different number of experiences, the answers were interpreted with this experimental dichotomy in mind.

Figure 2: Experiential overview of participants of 17 M&MM-Ps over a five year time period



Legend: *The pie chart colors signify the number of times a professional attended an M&MM-P; meeting 1 attended by 14 professionals, that meeting being their first, and meeting 2 attended by 11 professionals, for seven of whom it was their second meeting etc.; the numbers in the colored segments are the absolute number of professionals; the number in the center signifies the M&MM-P. This overview does not include the secretary, the researcher (attended since 2018), or the patient (with or without a partner/family member).*

Code tree: from a practice perspective to a learning perspective

Qualitative analysis of the interviews with professionals from the latter group, as well as observations of the role they take on in the M&MM-Ps, shows a trend towards deeper learning related to experience. The analysis based on 14 M&MM-Ps resulted in a code tree consisting of ten themes divided into three main clusters. Previously (Myren et al, 2020) the interviews were coded from a practice perspective, with a focus on how patient participation may be best implemented in the extant organization of work. Here, we analyzed the data with a focus on learning. The relationships between the two ways of coding are shown in Figure 3. The new themes were clustered depicting three domains of experiential learning that influenced behavior at the M&MM-Ps. We will discuss different themes in the three clusters, because several factors are at play and these can best be understood by explaining the narrative in which they occur.

Views on learning in a patient-centered improvement context

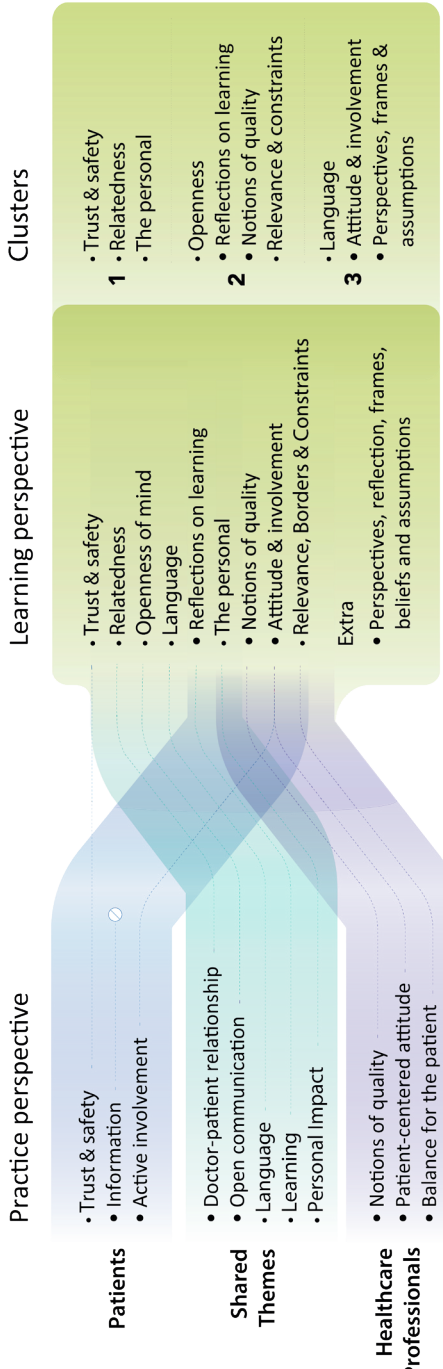
"for the benefit of the patient."

Cluster 1: Trust and Safety / Relatedness / The personal

The inter-relational and (inter)personal aspects of M&MM-P that emerged from the analysis shed light on the conditions needed to host an event that genuinely embraces the patient story as a starting point of learning form AEs. The main codes were related to trust, safety, a sense of relatedness and how M&MM-P affects attendees personally. These conditions align well with how healthcare professionals are used to interacting with patients, and which patients respond well to. Crucial for establishing trust seems to be a degree of openness, to be understood in terms of being transparent rather than being open-minded which is discussed below.

Patients feel safe during the meetings, which is due mostly to them trusting their healthcare professional, who has treated them and invited them for the M&MM-P. A well-organized meeting adds to that feeling: 'it gives a sense of trust, a feeling that everything will be alright' (patient 4). This seems to be unrelated to how often professionals attended an M&MM-P before, since every patient stated that they had an already established trust in their professional prior to the meeting. A way for professionals to create a relationship

Figure 3: Understanding M&MM-P from a learning perspective organized into 10 themes and 3 clusters



of trust before and during the meeting is to show their human side, e.g. by telling a joke or making small talk.

An unsafe environment may impact a professional's ability to be open with a patient. Safety is also established by the fact that M&MM-P is perceived as a team effort. Health care professionals felt safer to express their opinions freely because of this. Some consultants, though, noticed differences in openness with the patient present. Others did not seem to notice anyone holding back:

'And I think, when an adverse event occurs, healthcare professionals talk amongst themselves about what happened. So, I did not have the idea that people were holding back.'
(gynecological oncology staff member 12; attended 5 times)

Even though patients did not express feeling unsafe, some did feel tense. Patients explained that they accepted their situation and acknowledge that things can go differently than expected. Mostly, they were grateful for being alive at all. This attitude resonated with professionals within the department of gynecological oncology who have experienced several M&MM-Ps, perhaps more so because they do not view the M&MM-P as a preventive measure per se:

'A patient may be involved in the whole process, and included in the M&MM-P but may ultimately think that they need to put the blame on the organization. Well, they have the right to do that. But that will never be a reason for me to organize the M&MM without patients. I think that this [M&MM-P]…. will only have a positive effect.'
(consultant gynecological oncology 9; attended 5 times)

Observations showed that all patients responded positively to attending an M&MM-P and to professionals who attended the M&MM-P more often. This may mean that experiencing several meetings creates a (personal) sense of safety and trust and professionals could rely on patients responding positively. For example, a consultant from an external department who attended an M&MM only once questions whether healthcare professionals would feel safe to freely express themselves all the time. In this case, the professional's view of M&MM-P was that the meeting is doing two different things at the same

time, which could pose a constraint for either one of the perceived goals. When certain information is not shared during the meeting, it may limit the discussion and the focus on technical medical processes:

'That in the end you do it more for the benefit of patient, than to improve the process within the hospital.' (general surgery 15: attended once).

Professionals who experience overall trust from their patients anyhow, also express positive experiences of the M&MM-Ps, which may further develop their sense of safety and trust and they will continue attending M&MM-Ps. In the end, trust, openness (transparency) and personal elements seem to be the foundation for organizing an M&MM-P where attendees feel safe. Still, being open about what happened may also require experience with the format of M&MM-P as such.

"that we all thought, oh.. they experienced the adverse event in a very different way."

Cluster 2: Openness / Reflections on learning / Notions of quality / Relevance and constraints

In the context of M&MM-P, pre-existing ideas about what constitutes good quality of care, and how care should be improved determine attendees' ability to adapt and work in a patient-centered way. Views on learning are an integral part of those ideas and beliefs. In this cluster 'openness' refers to being open to different perspectives.

When professionals mention learning from AEs as a central component of the M&MM-P, they usually refer to what can be learned pragmatically, in a technical medical sense. However, M&MM-P encouraged learning at several levels, even if constrained by the notions of learning that professionals have. Patients also learned during the entire process of receiving care, up to the M&MM-P: *'After a while I started to understand their language' (patient, 1).*

In addition, they saw how the AE also affected their attending consultant, and how they try to cope with AEs. Patients seem to share the professional's perception that, regrettably, dealing with AEs is part of the work and related

to certain risks. It demonstrates the openness of patients to the reality of professionals.

'I do not think they could have done things very differently. I also think it is a bit of bad luck that something like this happened. I mean, I do not have the feeling that mistakes were made. And, if that were the case, then I would still think well… even that can happen, you know.'
(patient 8)

How M&MM-P is perceived depends on what professionals consider relevant. For example, according to the following consultant, quality is very much associated with having an in-depth discussion about the medical content. This seems to compete with how to respectfully involve the patient, showing how a pragmatic stance can lead to conceptualizing learning from AEs and person centered care as two separate things.

'… I think that is something we all struggle with; how do you involve a patient as much as possible in terms of how you treat them with respect, in terms of language et cetera, and maintain high quality.'
(registrar gynecological oncology 2; attended twice)

M&MM-P is viewed as something that needs to be done right, and efficiently, like M&MMs without the patient present. Part of this is being well prepared and knowledgeable about the case. An external consultant who attended an M&MM-P for the first time was not involved with the AE: *'I went to the meeting feeling somewhat unsettled. I thought, I have to join a meeting about a [patient] that I do not know personally, only by reading her file. And that is something I did not feel comfortable with.' (urology 13; attended once)*

Professionals who attended more M&MM-Ps reflected on a deeper level on the meetings, and get better at co-creating a session that is open and safe. Still, ideas about what is relevant keep on playing a dominant role in how they view patient participation in these meetings: *'there is a risk that people will not understand everything, ask irrelevant questions, or involve unnecessary topics.' (consultant gynecological oncology 11: attended 11 times)*

When starting out with M&MM-P, adapting to the (assumed) needs of the

patient made the meeting feel unnatural in comparison to the traditional M&MM. After experiencing several M&MM-P the pioneer group found a balance: the role of the patient became more prominent, while technical issues were also delved into and a more personal atmosphere was maintained. Observations showed that professionals asked the patient about their experiences more frequently.

'We look at [AEs] through the eyes of a healthcare professional and when the patient emphasizes something very different than we do, we can learn a lot from it. I can remember a meeting where that happened, that we all thought, oh, they [patients] experienced it in a very different way.'
(consultant gynecological oncology 4: attended eight times)

Taking time to really listen to the patients story demands and stimulates a certain degree of openness. The more experienced professionals master the skills to create this openness during the meeting and make the meeting more patient inclusive.

"the patient is joining us."
Cluster 3: Language / Attitude and involvement / Perspectives, frames and assumptions

The previously described themes (openness and notions of quality and learning) are grounded in the professional's belief system. In this third cluster we will describe underlying prevailing convictions, frames of reference and assumptions.

'Language' surfaced as an important theme, mostly in making M&MM-P accessible for patients. Particularly during the first M&MM-Ps most professionals struggled to achieve this and explained that it was difficult, 'especially in terms of terminology and how elaborately you explain something.' (registrar gynecological oncology 8; attended once). They did not want to give the patient too much or too complicated information, while from their perspective the quality of the meeting could be compromised by this. This was also the case for professionals from external departments wishing to clearly explain the AE without using the 'correct' medical terminology.

'He thought the meeting was not successful, because he was unable to share everything. He explained that what he shared at the meeting is different from what he defines as medically correct, because he had to adjust his language.' (observation fieldnotes M&MM-P 13, general surgery; attended once).

After experiencing multiple M&MM-Ps, professionals started to feel more comfortable using different types of languages (lay and medical).

'In the beginning we directed the story towards the patient; but we need to keep it more professional; and then you can do it in the language the patient understands. [M&MM-P] is not only for the patient, but also for the group, and the patient is joining us.' (consultant gynecological oncology, 4: attended eight times).

After a few meetings, a balance between lay and medical language helped to include patients as more equal partners in M&MM-P. According to one consultant, the professional perspective on patient-centered care determined how the team included the patient during the meeting. Gaining more experience also provided gave the professionals the confidence to select any patient for the meeting, instead of only the patients with whom they already had an established trust and personal relation with.

During an interview held in 2018, a healthcare professional explained

'…I do not know, it will be very different when you have a patient [who is partly paralyzed] joining the M&MM-P. We do not have a lot of experience with that.' (consultant gynecological oncology 7; attended five times).

One and a half years later, in 2020, the same, now more experienced consultant said *'It would be interesting to invite a patient who is very emotional, or a patient with whom something went very wrong. We have not experienced that before.' (observation fieldnotes research meeting, 2020; attended nine times).* This shows a perspective change and normalization of patient involvement in a variety of AEs.

Increasingly, these professionals also come to view M&MM-P as an overall design for learning, instead of doing two things simultaneously:

'It is a presentation for the group and the patient is part of that group, and does not have a special status. That is something you need to prevent, that the patient is excluded… When you emphasize that the patient is part of the team, yes, you are doing something good.'
(consultant gynecological oncology 9; attended five times)

Several underlying assumptions changed and were modified after professionals experienced multiple M&MM-Ps. Their attitudes shifted towards involvement of patients with a difficult history and feeling more at ease using modified language. This indicates a deeper level of learning that influenced their frame of reference around M&MM-P. Interestingly, such experiential learning was not always articulated, and professionals rarely reflected on their own frame of reference or expressed that they had changed their beliefs and attitude over time.

Discussion

The goal of this study was to understand the patient-centered innovation M&MM-P as a potentially transformative experience. We found that a patient-centered innovation creates more opportunities for learning when understood as a learning process. Professionals engaged in different kinds of learning processes depending on their experience with M&MM-P. The qualitative analysis led to the construction of themes and clusters thereof, which described these processes. Cluster 1 aligns with how professionals and patients communicate and relate to each other, enabling an established relationship based on trust. The processes in cluster 2 and 3 seemed to be more crucial for whether professionals in M&MM-P enter into deeper learning or not. As outlined in the introduction, this type of learning needs to influence the whole work environment if one is to make innovation sustainable. In the following paragraphs we will discuss our results and what a learning lens can do for establishing a more sustainable design of our patient-centered innovation.

First, in cluster 1 we found that safety, trust and experienced attendees were crucial elements in enabling the team to learn. Trust was partly facilitated by the use of body language that showed confidence and an eagerness to learn and be open. These 'non-verbal presentations-of-self' may support a context

of trust more rapidly for both patients and colleagues. (53) To establish a safe environment, it is important to be aware of when people in a group feel safe. Hierarchy and power imbalance can influence this and can interfere with feelings of safety and openness. Power structures may have both a positive or negative impact and can work across hierarchical ranks. (54) Our findings showed the importance of empowering the patient during the M&MM-P. For example, by sitting the patient next to their case manager; a familiar healthcare professional invited the patient to join the M&MM-P; and the moderator did not only focus on time management but also on summarizing, including the patient in the discussion and explaining technical subjects in lay language. Myren et al. (2020) showed that patients felt safe to speak comfortable about their experience. This does not include evidence on the experiences of power and empowerment amongst healthcare professionals themselves. In general, psychological safety can be achieved when members of a team hold a shared belief that the team is safe for interpersonal risk taking. (55) Setting the boundaries in such a way may also, paradoxically, undermine co-created safety by preventing constructive use of uncertainty and vulnerability. On the other side of the spectrum, openness and being personal may also create too much vulnerability. Safety may decline when something is expressed honestly which clashes with another participant's values or ideas. (56) This may result in situations where concerns are not well addressed or types of emotions arise that are not dealt with in the right way. However, if emotion and safety are balanced, this allows for affective learning that may be very powerful. In general, professionals are not expected to cry or show emotions, but several consultants did mention the impact of emotions and the possibility of learning from them: *'you may learn more when the patient is present because hearing their story is impactful'*.

Second, the observable changes raised in cluster 2 aligned with more equal value being given to the knowledge system of the patient. The type of learning points that resulted from the patient's input during the meetings partially validated the patient's (experiential) knowledge. Learning points from the meeting usually relate to relevant clinical practice and are based on the knowledge of the professionals involved. (57) Even though professionals came to perceive the patients' experience more and more as relevant during the M&MM-Ps, these points were often not described in the reports. Authoritative knowledge systems can gain superiority due to consensus or

structural use. From that viewpoint, alternative knowledge systems may be seen as backward or ignorant. (58) Although explicitly, many professionals adhere to a knowledge system linked to a more narrow conceptualization of evidence-based medicine, by engaging in M&MM-P they seem to appreciate the (experiential) knowledge of patients more.

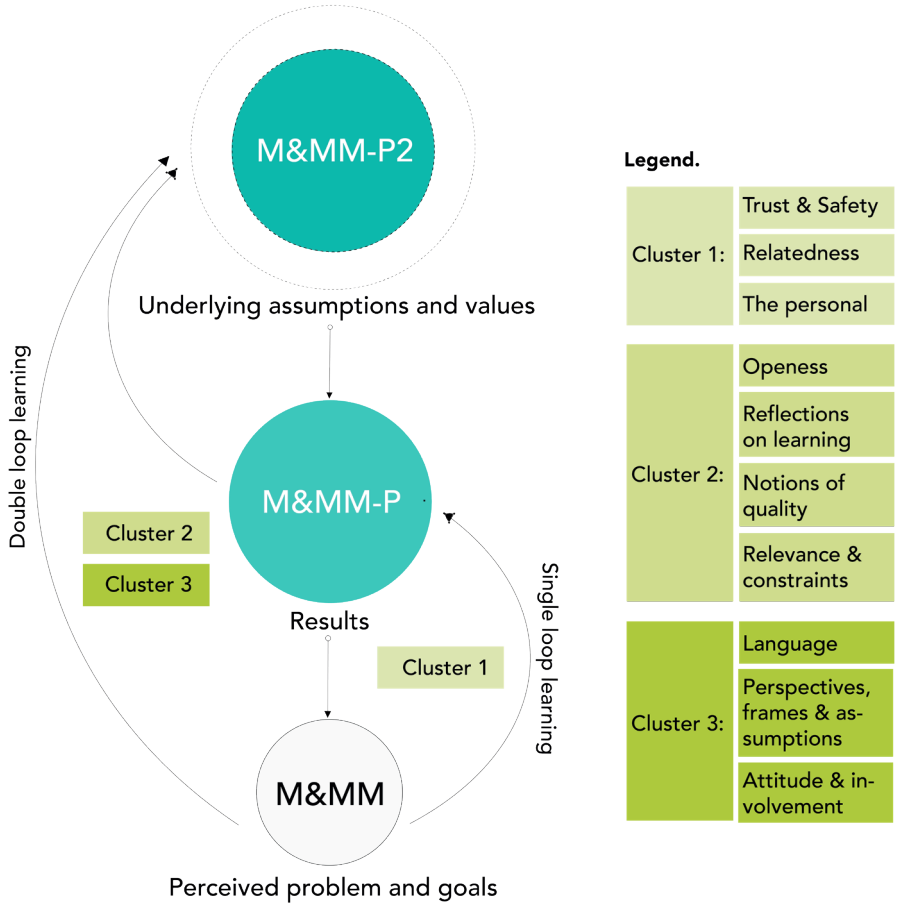
Third, cluster 3 encapsulates themes that relate to professional's belief system and professional identity. All healthcare professionals pass through a professional identity formation process during their training and individual professional experiences. (59) Increasingly, professionalism is also shaped by society's expectations and needs, and the so-called patient movement. (60) In our study we found that in real life patient-centered care consists of aspects such as providing openness and information after an AE, but within the borders of what healthcare professionals experience as safe. The borders professionals may need to break through are partly related to how they express themselves. For example, cluster 3 showed a transition in how professionals changed and started using a different, more patient-centered language. Language holds an important role in identity reproduction and formation. (61) Within the medical realm, language is important in understanding colleagues and may promote socialization in medical teams. Using more accessible language to include the patient at M&MM-Ps may therefore compromise their professional identity. However, the patients in our study have often been under treatment for a longer period of time and even indicated that *'they started to understand their[professionals'] language'. (62)*

The three clusters highlight a trend towards deeper learning, which may prove crucial if we are to improve person centered care. Making healthcare practices more open and inclusive begs for understanding it as a place of learning. To be able to do this, practitioners need to rethink their perceived practice problems and challenges, but problematizing underlying assumptions.

For this, we have looked at the M&MM-P design from a theoretical lens provided by Argyris' idea of single and double loop learning (Figure 4) . (63) Single loop learning occurs when new ways of working are in line with, and enable, current policies. (63) In figure 4 single loop learning occurs between M&MM (white) signifying the goal of the M&MM and the perceived problem (AE); and M&MM-P (grey, middle) signifying the results (learning points)

which are the outcome of the meeting. Learning processes in single loop learning often do not affect underlying beliefs or convictions but rather add to, and agree with, the healthcare professionals' frame of reference. Cluster 1 is part of a single loop learning process because professionals seemed to be comfortable in relating to the patient and creating a bond of trust. However, underlying assumptions and values arise with M&MM and M&MM-P. For example, the assumption that the M&MM-P may cause harm to the patient, or ideas about how the quality of the in-depth discussion may be lower with patients participating. In double loop learning professionals challenge these underlying assumptions and values for a deeper level of learning to occur. (64) This is explained by clusters 2 and 3, which describe a change or transition.

Figure 4: Designing the experiential learning landscape of M&MM-P, based on Argyris, C. (1978)



An important condition for double loop learning is openness to new experiences. The result of double loop learning is visualized in figure 4 by M&MM-P2. M&MM-P2 is a situation where professionals challenged their underlying assumptions and were able to change them (the first dotted line around M&MM-P2). The dotted line shows that learning does not only occur within the M&MM-P, but should result in learning in the entire department outside of the meeting. In our study we found that double loop learning is more likely to occur after experiencing multiple M&MM-Ps. We also found that experienced professionals were better able to discuss AEs in more accessible language, while professionals who only attended once struggled to do so. However, due to a learning environment at M&MM-P2, it may take new attendees displaying openness fewer experiences to take the step into double loop learning (M&MM to M&MM-P2). Some professionals may need to pass through double loop learning a few times to experience M&MM-P2 because their underlying assumptions keep arising and are not challenged in M&MM-P. During the research project our team also attempted to introduce M&MM-P to other departments. This was difficult to achieve due to similar assumptions that arose for different professionals (Myren, pers.com.). Their assumptions may need to be challenged as well, which requires double loop learning. Moreover, double loop learning may impact the workplace outside the M&MM-P2. The second dotted line around M&MM-P2 in figure 4 signifies a resonance between M&MM-P2 and workplace learning. For example, if professionals' beliefs on patient participation change, that may impact on other clinical work that involves patients and represent a step away from a mere focus on learning points as an outcome (M&MM-P). When healthcare professionals become more aware and reflective of their changing perspectives, they may use the same approach in other healthcare delivery contexts. (65, 66)

This study's strengths lie in the data collection and- analysis with an interdisciplinary research team and the participatory action research providing the researcher with a better understanding of the dynamics within the team of healthcare professionals. A limitations of the study is that it includes no interviews prior to the start of M&MM-P in 2016, because the research started in 2018. Although the interview transcripts provided the right information for this study, we may have found more specific or detailed information if the interview transcripts were less focused on practical aspects. Secondly, we are

not sure whether the two consultants who were part of the research team, as well as the M&MM-Ps, learned more than other colleagues because they were part of the research meetings. The discussions in these meetings may have accelerated their learning curve. Thirdly, we explained that AE's selected for the M&MM-P were seen as AEs with a learning potential according to the consultants. However, this choice is still based on the frame of reference of that healthcare professional. We did not specifically formulate what professionals wanted to learn and why they selected a certain patient. This selection may include assumptions about what learning entails according to professionals. The fact that these assumptions changed became clear in the results where a consultant was interested in inviting 'challenging patients'. Therefore, more research is needed to understand how the perception of healthcare professionals on the learning potential of patient's AE changes and whether they are (more) concerned with reaching person centered care and improving quality of care.

In conclusion, prolonged, repeated experience with M&MM-P resulted in changes in behavior and perceptions of healthcare professionals about person centered care and patient participation. The basis for accelerating learning within innovative contexts that involve patients calls for healthcare professionals to be open and willing to push the boundaries of normative ideas about 'quality of care' and welcome workplace learning. These insights from a learning angle may help develop a design-based approach to patient participation as both a vehicle and a goal of care improvement in different contexts. (67)

Acknowledgements
The authors wish to thank all the patients and healthcare professionals that joined the M&MM-P and participated in this research.

Funding/Support
None

Other disclosures
None

Ethical approval
Ethical approval has been waived by the Ethical Review Board (case 2018-4713).

Disclaimers
None

Previous presentations
None

Data sharing
Upon reasonable request.

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chapter 7

general discussion

General discussion: Paving the way for patient-centeredness in quality improvement

This thesis presents new insights on the development, implementation and learning processes of patient participation at the morbidity and mortality meeting (M&MM) at the Radboudumc gynecology department. The objective of the thesis was to understand how a patient-centered innovation can be safely implemented in clinical practice, and whether it encourages participants to learn and change their behavior, and achieves improvement in care. Our M&MM with patient involvement required various designs to safely include patients in the discussions during the meeting. We found that the voice of the patient can help achieve the most important goals of an M&MM: to discuss and learn from adverse events (AEs) to improve and achieve safe healthcare for future patients. (1)

In this chapter we explore how to incorporate the findings from a practice and learning perspective towards implementing patient involvement at the M&MM in different departments and hospitals. First, we focus on the level of the healthcare professional, discuss resistance to patient involvement and present suggestions on how to overcome barriers with strategies for implementation. Second, we focus on the team and organizational level and discuss what is needed to start implementing the M&MM with patient involvement from a learning perspective, taking workplace-based learning into account. Finally, we discuss future perspectives for practice and research.

Figure 1. A time-based outline of the designs to improve the M&MM over the course of the study period

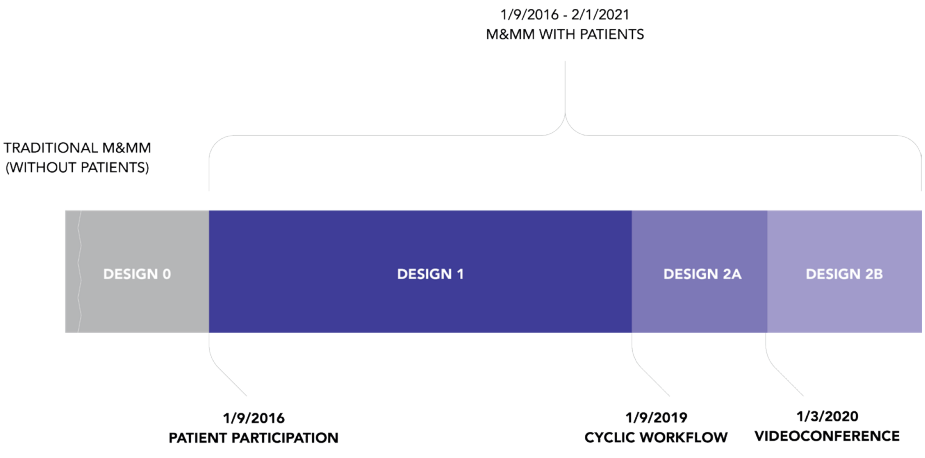


Figure 1 depicts an overview of the designs of the M&MM introduced over the course of the study period of this thesis. Design 0 represents the initial design of the M&MM in the years prior to September 2016 when patients were not involved at the regular meetings. Design 1 was developed to organize an M&MM with in-person patient participation. Two additional designs were then developed: design 2A to improve implementation of learning points in a cyclic workflow including a Plan-Do-Check-Act (PDCA) cycle, and design 2B to facilitate patient participation via video conferencing. The designs were studied within a team that hosted monthly M&MMs with patient involvement. Qualitative research methods were used to study behavior and change processes. Currently, all designs are offered as common care at the Radboudumc gynecologic oncology department.

In the following sections we will discuss the main findings in this thesis, which include:

- Patient involvement at the M&MM can be safely implemented for both professionals and patients with investment of time and with practical and communicative adjustments to the existing M&MM (chapters 3, 6)
- Patients showed trust and gratitude during the M&MM which helped in accepting and understanding what had happened to them (chapter 3)
- Involving patients at the M&MM required openness from professionals around AEs and openness to change (chapters 2, 3)
- The presence of a case manager (or nurse) is important in supporting the patient before, during and after the M&MM (chapters 3, 4)
- Professionals need to be aware of the lack of nonverbal communication when patients participate via videoconference (chapter 4)
- A cyclic workflow alongside motivation and commitment by professionals promoted the successful implementation of learning points from the M&MM (chapter 5)
- Professionals learn implicitly and constantly when patients are actively involved (chapter 6)
- Patient involvement at the M&MM can be a potentially transformative learning experience for professionals that may also change what they constitute as patient-centered or 'good' care (chapter 6)

Challenges for practice

The main point of discussion is how to implement patient involvement at the M&MM in different hospitals. Although numerous hospitals currently advocate patient participation as a form of healthcare innovation and quality improvement, the implementation of active patient involvement is not easy. Resistance to change is common within an organization and can make it difficult to effectively and successfully implement a new workflow. (2, 3) This requires behavior change, which is difficult to achieve. In this section we will discuss aspects of resistance to patient involvement and strategies for implementation.

Resistance to patient involvement

In our department the conceptualization of patient participation at the M&MM started with support from our management and was developed by one of the consultants with various stakeholders (members of the patient board, nurse, case manager, quality department, other consultants). We did not face resistance from the team to starting to invite patients to attend. Despite our positive preliminary findings, however, we did encounter challenges and resistance from professionals in other departments. Eventually, two departments considered inviting patients to their M&MM and some external hospitals expressed interest. The most challenging issues expressed by professionals from other departments included the difficulties of discussing sensitive topics in front of the patient, the fear that the quality of technical/medical learning points would decrease, and that patients would not benefit from attending the M&MM as they would not understand the information or were too emotionally involved. Moreover, a number of professionals suggested that their meeting structure was not suitable for patients to participate: patients might not be able to attend due to their physical health after surgery, several AEs are discussed in one meeting (lack of time), and in some surgical departments the M&MM mostly functioned as a way to correctly register AEs in the electronic patient file instead of reflecting on and learning from the AE. These issues showed us that a clear guidance on how to improve the M&MM is necessary for other departments. This research has shown that patients responded well to medical information during the M&MM, most of the information was not new to them, and healthcare professionals recognized the benefits of involving patients. Based on the

experiences of patients and professionals, we found that all sensitive issues could be discussed with patients at the M&MM by adjusting language and adopting a respectful tone. Moreover, patients were grateful to be able to attend the meetings.

The fact that implementation of patient involvement in daily practice is not easy is due to resistance among professionals to involving patients in their care. A review by Cahill (1998) claimed that a change in healthcare philosophy, attitudes and implementation is needed to adopt patient participation, which is a lengthy process. (4) The resistance professionals experience may partly explain the reasons behind this lengthy process. Although patient involvement is justified by professionals because they attach importance to patient autonomy, it may also be justified as self-interest to avoid legal repercussions. (5) During presentations of our research at international conferences, professionals assumed or were afraid that attendance of patients at the M&MM would increase the number of lawsuits. Although legal repercussions after AEs were not mentioned by professionals in our study - and are possibly not as common in the Netherlands compared to other countries - it may constrain hospitals in taking steps towards patient participation at the M&MM. This is due to the fact that professionals need to feel safe to openly discuss AEs with their team and the patient. Open communication is key. (6)

Besides legal repercussions and openness, barriers may also arise relating to the patients' mental and physical health, and professionals' fear of time-consuming discussions about topics that they do not see as relevant. Professionals may also avoid some discussions due to insufficient time or inability to handle them well. (7) Some patients may resist participating due to a primary focus on their illness, while others may not want to be labelled as 'difficult' and are afraid that it may jeopardize their safety. (8) Moreover, patients may be unsure whether their feedback will improve safety of care. (8, 9) Other research supported this fear by showing that professionals may perceive patients less favorably if their behavior is confrontational or if they ask about potential errors. (10) In our study, however, we found that all patients who were able to attend the M&MM were willing and curious about participating and professionals were interested in their opinions. We found that patient-doctor communication is an important factor that stimulates

patient involvement and a well-balanced exchange of information.(chapter 3, 4)

Professionals' resistance to involving patients also depends on organizational willingness and ability to change. (11) The barriers to patient involvement are diverse and the specific context of a hospital can make it challenging due to barriers such as a heavy workload, lack of time and other priorities. (12) Therefore, implementation may require different strategies that relate to both practical and organizational elements.

Strategies for implementation

Various strategies and conditions are necessary to implement research outcomes into daily clinical practice. (12, 13) Based on the results of this study, a combination of top-down and bottom-up approaches may be necessary to start implementing patient involvement at the M&MM and eventually achieve sustainable change. (13) A top-down approach includes support from the hospital board, regional directors, and/or management, whereas a bottom-up approach includes motivating individuals and teams, and taking all perspectives into account.

Strategies for implementation: the organization

A top-down approach to implementation entails getting professionals in leadership positions, such as managers, directors, or a board, to convey the message that an M&MM with patient involvement is beneficial and necessary, and needs to be implemented. This may even be a precondition to start involving patients. Overall, the support of management and leadership is crucial during implementation. (14) Low leadership engagement and limited resources can pose barriers to implementation. (15, 16) A significant proportion of professionals in leadership positions need to present plans for implementation in such a way that those who execute them acknowledge the benefits. (17) In addition, when presenting the plans, the fact that innovation also needs to be adaptable to the context where it is implemented needs to be taken into account. (18) In our study, support from leadership and management was already present and small adaptations to the local context were made regularly by putting the research results to practice. However, more research is needed to understand what is needed in different departments and contexts.

An often mentioned barrier to implementation in healthcare is lack of time and funding. (19) Therefore, it is important to investigate any underlying reasons, or other barriers, for example by using different frameworks. (20) In our study we found that it takes time to develop and eventually to organize monthly M&MMs with patient involvement. Currently our department considers patient involvement as part of standard care, which shows the importance of the policy management introduces. Other departments already host M&MMs, and time is therefore already reserved to organize them. However, with patient involvement more time is required to prepare the M&MM more thoroughly, and to invite the patient and all healthcare professionals involved. (chapter 3, 4, 5) Our study showed that combining actual implementation with a research project benefitted the implementation process, for example by observing the M&MMs and interviewing attendees, and using the opportunity to use new insights to keep improving the M&MM.

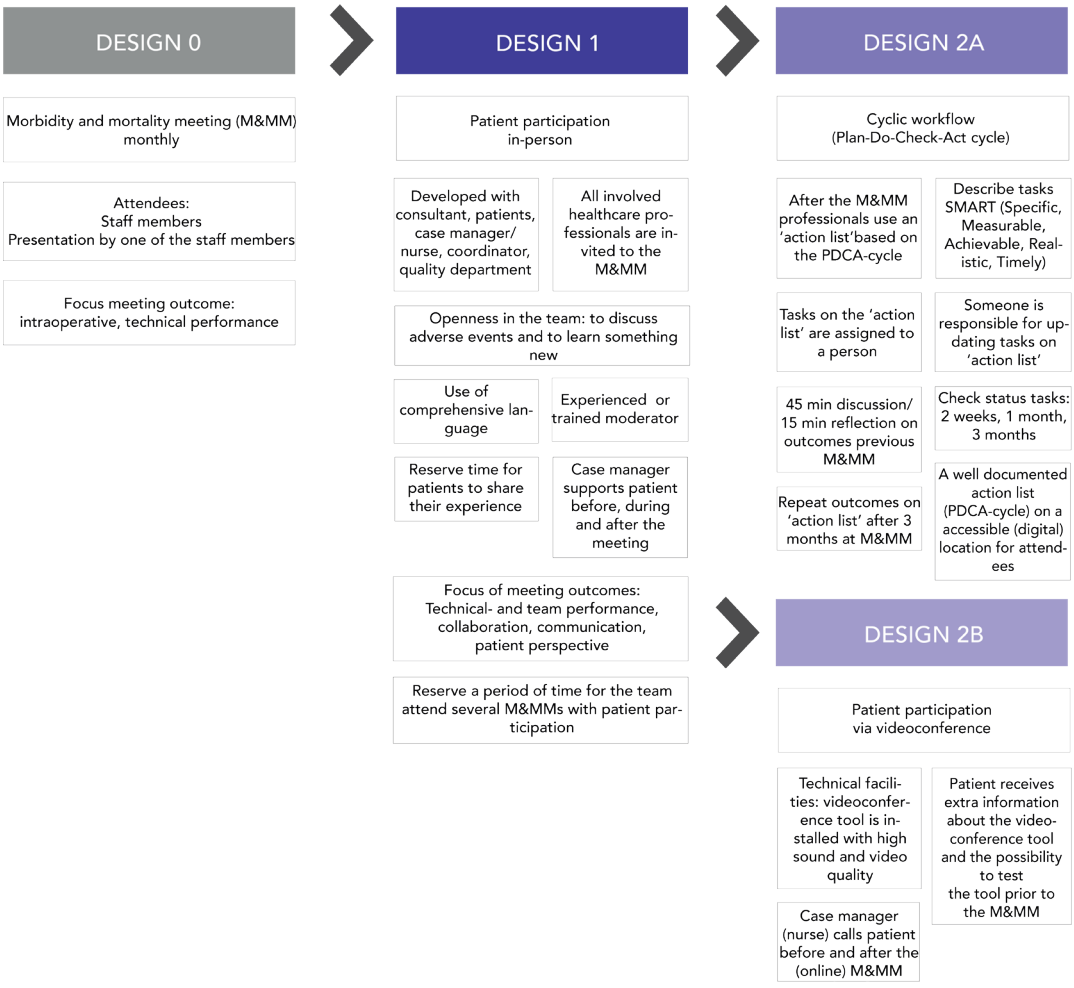
Strategies for implementation: the team and department

A bottom-up approach entails motivating the individuals in the team and department to start implementing patient involvement. The first step is to convince professionals that patient involvement works and achieves the goals they view as important in healthcare improvement. (21) A team member may take on a leadership role, taking the lead in this process and prioritize patient involvement. We found a way to relay the benefits of patient involvement by inviting other consultants (e.g. from the departments of urology and general surgery) to join the M&MM with patient involvement. That enabled them to see how we organize the M&MM and in what way patients contribute to the discussion. These encounters with patient involvement at the M&MM, including the attendance of registrars, may create positive stories and interest for this innovative approach in other departments. When the AE is experienced as a shared responsibility in the team it can create safety and openness during the M&MM. This was also vocalized at the start of the M&MM in our research: all the healthcare professionals participated to learn from the AE without putting the blame on one person. That made it easier to discuss factors relating to human relations generated important and diverse learning points. The literature also shows that professionals may learn from patients' experiences, even when they are vocalized as a complaint. (22)

The individual patient also needs to feel motivated and able to join the meeting, which starts with how they are involved in their care. Having empathy or being able to adapt to the patient's needs while communicating, appears to be a skillset that many professionals still need to learn and/or keep practicing, even after years of training. (23, 24) To improve communication, during their medical training, students should therefore focus on the patient as an equal partner in their care. A significant part of changing dynamics in communication is stepping away from dialogues dominated by the professional and increasing active participation by patients. (25) In addition, being able as a patient to collaborate and discuss with a healthcare professional may lead to positive outcomes and to better managed care. (26)

In our study, several of the above-mentioned conditions were present for the gynecologic oncology team, including support from management and professionals in leadership positions setting an example. We found that experiencing several M&MMs with patient involvement allows professionals to learn about the benefits of patient involvement and how to involve patients. (chapter6) Figure 2 provides an overview of the main practical adjustments of each design of the M&MM with patient involvement (mentioned in figure 1) that we implemented during the research. The basic design 0 was already in place for years and organized each month. Implementing design 1 was the most important step in starting and also in normalizing patient involvement at the M&MM for professionals. In addition to the practical adjustments to the meeting (figure 2), patient involvement stimulated different learning processes. In the following section we will elaborate on how these processes may support other professionals and hospital departments in starting to involve patients.

Figure 2. Practical adjustments to the M&MM with patient participation for each design



Placing the patient at the core of quality improvement

In this thesis, quality of care is framed as something that is not static, but context dependent and personal, and therefore requires continuous learning. The patient's perspective can be seen as an integral part of quality of care. Viewing the patient as a partner and placing them in a more equal position alongside healthcare professionals acknowledges their role as an active participant in their care. However, we found that acknowledging the patient's voice as crucial for establishing high quality care is a challenge for professionals. This challenge can be overcome when the patient's role is recognized as a valuable part of how professionals learn in the workplace. (27) The patient is part of this learning process.

Our research can be seen as having an innovative approach that takes the patient as partner into account on both a conceptual and practical level. (25) This approach represents an invitation for patients to participate and puts a focus on the patient as a person. (28, 29) We found that patients appreciated the participatory role and almost all patients who were able to join preferred to attend the M&MM. We will further discuss how learning processes can be made an explicit part of the implementation process of patient involvement at the M&MM.

Participation and the patient-professional dynamic

The objective of this thesis is to understand how a patient-centered innovation can be safely implemented in clinical practice, and whether it drives participants to learn and change their behavior to ultimately improve care. Establishing safety can be partly explained by the experiences of both patients and healthcare professionals who were both positive about attending.(chapter 3-6) Overall, there were no unsafe situations observed and professionals and patients expressed that they felt safe. However, professionals experienced some challenges relating to their assumptions and underlying frames of thinking. The experiences of patients and professionals, and learning processes related to changed behavior and perceptions, contributed to a sustainable and improved M&MM.

Research question: What are the experiences of patients and healthcare professionals with an M&MM (in-person and online) with patient participation?

We found that notions of quality of care and quality of the M&MM relate to how patients are involved at the M&MM. Professionals need to see the patient as a fellow traveler on the road towards improved quality rather than a factor that could compromise the quality of the meeting. Such initial doubts could be mitigated when patient involvement proved to lead to well-prepared meetings that provided a different perspective in the discussions, leading to more diverse learning points.(chapter 3-6) However, in a healthcare setting there is a power imbalance in the patient-professional relationship that can influence the content of the meeting and that needs to be acknowledged. This power imbalance occurs when the patient does not receive credibility from the professional for what they are sharing. This is defined as testimonial injustice, which needs just credibility to move towards a partnership and equality in the patient-professional relationship. (30) De Boer (2021) performed research in the Netherlands on how challenges in achieving patient involvement are related to underlying assumptions that create testimonial injustice. (31) De Boer warns not to underestimate patient knowledge and discusses how patients can be emancipated from the dominant expectation that patient participation may only have benefits when they have or acquire biomedical knowledge. This undermines the value of the different types of knowledge patients have, including experience of the health system. And it also undermines the role their knowledge can play in improving the quality of care. This thesis may reinforce such a step towards the empowerment of patients, while moving away from tokenism or their symbolic participation. Tokenism, such as including patients without letting them voice their opinion or concern, is another effect of power imbalances between patient and professional that implies that patient-centered care is achieved only if the patient is included in a symbolic way. (32) When the patient is not included and taken seriously, it may have negative consequences, for example it may not lead to meaningful change in daily practice or achieve any of the goals. Ocloo (2020) suggests that when implementing a patient-centered innovation it is important to consider the power imbalances on all levels of the health system, as these imbalances are inherent to the organization, the policies and the interaction between patient and professional. (33)

Giving patients a voice by joining the meeting may benefit them by increasing their willingness to participate more in their care. (34) However, having a voice does not always mean that you are heard. 'The voice' can be framed as a way of showing that a person has agency and a presence. (35) Agency can be seen as the amount of flexibility a person has, or the amount of means that a person can choose from to achieve something. (36) The context in which a person has agency also determines the amount of flexibility. Therefore, the context in which patients participate needs to provide enough flexibility for them to use their voice and to make sure they are heard: giving them enough time to share their experience at the M&MM and letting them know in what way the learning points of the meeting are implemented in practice. (chapter 5) In addition, we found that while implementing the M&MM with patient involvement you need motivated professionals who take the patient experience seriously.

Research question: In what ways do patients and healthcare professionals learn and change their perspectives and behavior after attending M&MMs with patient participation?

When professionals engaged in deeper levels of learning, their frame of reference on patient involvement at the M&MM changed. In turn, this led to them express a desire to discuss different types of severe AEs with patients in order to learn even more and improve patient care. (chapter 6) On a practical level, professionals adjusted their language and a route was set up to invite and prepare patients to the meeting. Seen from a learning angle, professionals seemed more open and eager to integrate the patients' perspective in the discussion. On this level commitment is important, which can be only to oneself, to someone else, or to each other. (37) Preferably there is mutual commitment, which our findings also suggest is the case as professionals inspired and increased commitment after experiencing a successful M&MM. (chapter 5, 6) During implementation it may be important to determine what motivates professionals in order to create commitment.

Next to commitment and motivation of professionals, we found that repetition of tasks may support the implementation of meeting outcomes (e.g. learning points). Repetition also led to normalizing the importance of taking on tasks and finding time to implement them in daily practice. A reflective culture

can support the integration of new ways of working with reflective practice. (38) Reflecting on tasks has been a challenge at the M&MM, because tasks were often being checked rather than reflected upon. However, this research functioned as a way to support professionals in their reflective practice by asking questions about their experiences at the M&MM during interviews. Incorporating the implementation with research can therefore be a first step towards promoting reflective practices. Reserving time to reflect on these issues during implementation may benefit professionals as it offers more opportunities to learn something new. (39)

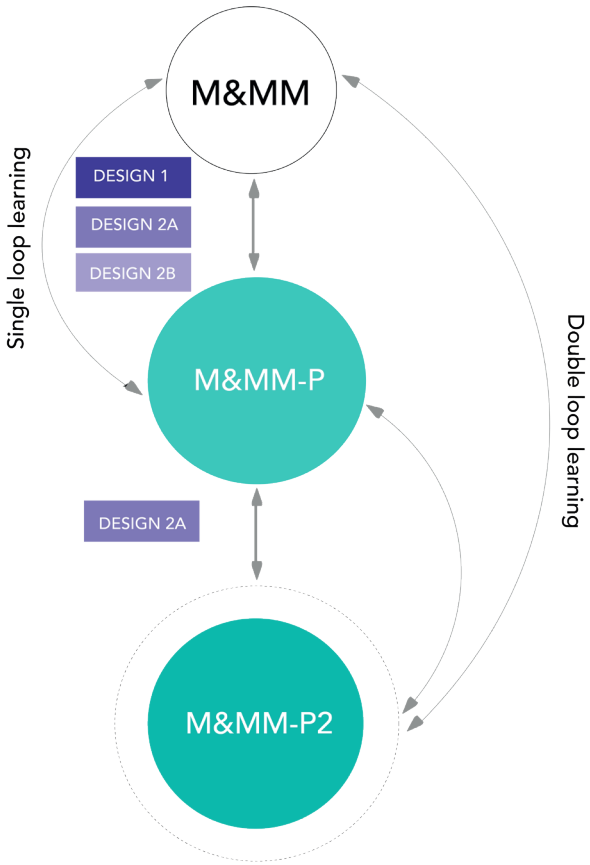
These findings outline various results that are relevant for the patient and the professional. However, when looking at quality as a learning process we also need to take the learning environment into account. The learning environment can be the hospital context, the department, or the attendees, including professionals and the patient. This environment may influence the implementation of patient involvement at the M&MM because it can support daily learning and reinforce transformative learning. (40) Therefore, we will reflect on the environment in which professionals learn, and in which patients have a specific role. Importantly, we do not view the learning environment as set apart from the learners. The learner and the environment are not so much seen as separate entities interacting, but more like intertwined constructs.

The workplace as a learning environment

The learning environment of professionals is an important aspect during the implementation process of patient involvement at the M&MM. For their part, patients influence workplace-based learning by professionals and may influence what professionals constitute as patient-centered care. Figure 2 is a practice-focused guidance showing what is necessary to start with patient involvement at the M&MM, while figure 3 shows the learning process that is continuously going on in the background. This is a constant process that needs to stay active. In this section we explain how the environment of professionals stimulates learning, and especially when the environment changes.

Figure 3 (from chapter 6) places the designs into single and double loop learning. Single loop learning (M&MM -> M&MM-P) here describes learning how to involve patients on a practical and relatable level, without underlying assumptions being challenged or questioned by the professional. We found that even quite fundamental factors may be associated; for example, transparency and being open about what happened reside on this level. After all, healthcare professionals are already able to discuss the AE with colleagues and the patient, regardless whether they engage in frame reflection or not. This was visible when design 1, 2a and 2b were implemented.

Figure 3. Argyris' (1978) model of double loop learning including the three designs



Legend:
morbidity and mortality meeting (M&MM); morbidity and mortality meeting with patient participation (M&MM-P); morbidity and mortality meeting with patient participation understood within a learning environment (M&MM-P2)

When taking the step from involving patients (M&MM-P) to doing this in the context of improving the workplace as a learning environment with patients (M&MM-P2), other factors come into play. Professionals may, for example, question whether their way of thinking is open towards their colleagues and the patient. When reaching M&MM-P2 it is important to encourage professionals to question and reflect on their own notions of quality of care and patient involvement. In double loop learning, attendees reach a deeper level of learning and may change their frame of reference on these topics. (41) Figure 3 shows that design 2a can both stimulate single and double loop learning, depending on how professionals are encouraged to reflect on their own convictions. For example, when professionals only 'check' the task related to the meeting outcome at the end of the M&MM, they will not reach a deeper level of learning. In order to stimulate double loop learning professionals need to reflect on how and why the meeting outcomes led to successful healthcare delivery, and what the effects are on practice and, for example, patient safety. Patient involvement at the M&MM may also facilitate a more patient-centered environment outside of the meeting, such as when healthcare professionals take on more opportunities to involve patients in other settings. The team of professionals from this research remained in the dynamics of M&MM-P2 and learned a new way to discuss AEs with patients. This is currently normalized, as it is now installed as common care and no longer considered as something new. The normalization of patient involvement seems to be a condition to facilitate a learning environment at the M&MM.

Based on the results in this thesis, several aspects in the workplace environment may have encouraged the team and department to find more learning opportunities. First, at the M&MMs, not only different types of people (professionals and patients) attended, but also a variety of cases with different levels of severity were discussed. This may influence the type of information discussed, or even the impact and emotions that were shared during the meeting. For example, in one of the observed M&MMs, hosted by the geriatrics department, a family member of a deceased patient attended the M&MM. This impacted the attendees due to the informative and respectful tone in which the case was discussed with the family member. In such an environment the level of learning can change, due to the fact that emotions influence how people process and interpret information. (42)

Second, an environment in which professionals dare to act differently than the system in which they work benefits change. (43) Third, in the team in which the M&MM with patient involvement is studied there already seemed to be a safe environment to discuss AEs and to actively take on new ways of working, and there was support from leading figures and management. These aspects supported the team in stepping into single loop learning more quickly. When there is not a safe environment to discuss AEs within the department or team, it will take more time to comfortably discuss them with the patient. Reflective practice is important to step into double loop learning and to improve workplace learning. (44) Although the research partly facilitated this, it takes more time and adjustments to keep reflecting on what has been learned at the M&MM and what that means for daily practice. However, we found that a lot of what was learned by attending the meeting, was learned implicitly without a lot of reflection. Implicit learning can be achieved by gaining more knowledge without consciously making an effort to learn and without having any knowledge about what you have learned. (45) When the research on patient involvement at the M&MM started there was no explicit goal to teach professionals how to involve patients. The fact that professionals changed their behavior was related to levels of implicit learning in a safe environment. (45) This level of learning would have been difficult without a team that was willing to keep attending the M&MM with patients. Fourth, when the wider environment in the hospital already includes patients in many different contexts and has reflective learning practices installed, or has an open culture, stepping into M&MM-P2 (double loop learning) may occur more quickly. However, in a context where this is not common within a department, it may take more time to reach a deeper level of learning and needs to be considered during implementation. (46)

Each hospital department will take a different amount of time and will need to go through different learning processes to implement patient involvement at the M&MM. However, this thesis has shown that a team will always learn when patients attend the M&MM, either explicitly or implicitly. Therefore, when a department starts with the practical and organizational adjustments of the M&MM to invite patients it will step into single loop learning. This can be experienced as safe and will have benefits for both patients and professionals. A strong team with openness and respect for one another will support this first step. Although workplace learning happens implicitly,

a second step may be to include explicit learning, such as regular reflection in an educational format. All departments may benefit from finding ways to better involve patients which improves care and may lead to changes towards a culture of patient-centered care.

Future perspectives in practice and research

In this final section we will go into methodological considerations, what type of collaborative action is important for practice and future research. Finally, we present a guidance with practice-based advice on how to implement patient involvement at the M&MM based on this thesis.

Methodological considerations and the impact of COVID-19

The research in this thesis faced a variety of challenges. First, it was not possible to compare data on the experiences of healthcare professionals to the situation and dynamics in the meeting prior to the start of involving patients. When the research started the team had already organized a few M&MMs as a pilot and this also influenced their initial perspective. Second, at the start of the study we aimed to do a comparative study in different departments. However, due to implementation challenges this was not possible. In addition, the COVID-19 pandemic caused departments to change their priorities. Although there was a similar prioritization in our own department, the M&MMs resumed after a few months as they were seen as important in the primary process of care. COVID-19 provided opportunities to further develop patient involvement via videoconferencing and we consequently made changes to our research.(24, 25) Prior to the pandemic, an M&MM with online patient involvement was hosted in 2019. An advantage of implementing online patient involvement during COVID-19 was that the technical facilities around video consultation and meetings in the hospital improved considerably.

We discovered the strengths of the research set up. For example, working within a multidisciplinary team implied diversity and different perspectives during the research design and analysis. Although it was challenging to integrate and align these perspectives, it brought new insights. Furthermore, due to the iterative nature of the research it was possible to combine

research, reflection, feedback and small adjustments to the meeting during the implementation process. This was important for the overall improvement of the M&MM.

Future perspectives in practice: collaborative action

In order to change the M&MM and to make sure other professionals are open to the idea, the Board of Directors ('Raad van Bestuur'), regional directors or management of the hospital will play an important role as they oversee patient quality and safety. (47) Moreover, it aligns with the goals of the Radboudumc to improve the quality of care and treat the patient as a partner. At management level, patient participation at the M&MM can be implemented as a department-wide project and included in plans with the head of departments. In addition, collaboration with a research institute, for example to integrate research with the implementation process, would benefit the process and commitment of professionals. For departments outside the Radboudumc and even in the various oncology chains, we provide advice on how to start organizing and implementing patient involvement. In addition, we recognize the need for support for professionals.

In order to maintain and sustain a well-organized M&MM with patient involvement in the department there is a need for an invested coordination team with allocated time for tasks related to preparing the M&MM. This includes a coordinator of the meeting and a core team with experience to select AEs, invite patients, collaborate with case managers and invite other departments to attend. The M&MM needs to be seen as a high priority in all departments of the hospital to continuously improve care, have tailored dialogues with patients after AEs, learn from communication and collaboration based on patient's experiences, and move towards a future that aims at lowering morbidity and mortality rates.

Patient organizations (inside and outside the hospital) may also help to generate more exposure for patient participation at the M&MM. Currently, these organizations are involved in research, advising on policy in hospitals and helping patients to better understand their conditions. The Dutch Patient Federation (Patiëntenfederatie Nederland) supports patients with questions related to their experiences. A patient organization specifically for women with a gynecological cancer ('Olijf') brings together patients with similar

conditions or experiences and shares information. These national patient organizations and the Patient Advisory Board in hospitals should be involved in the implementation process and know about the benefits of patients attending M&MMs. Within their network they can make patients aware of what a M&MM is and what it aims to achieve. Members of the Patient Advisory Board of our hospital were involved in developing the first guidance to involve patients, and were part of the steering group which gave feedback on the research design, results and outcomes. In our research we heard that patients were often not informed about the M&MM and the outcomes of such meetings. These organizations can notify hospitals that the option for patients to attend an M&MM should be available. As the role of patient organizations is constantly evolving and growing, they should be included as a partner in the process of implementing patient-centered innovations such as the M&MM.

A step towards lowering resistance to patient involvement among professionals is to promote openness and being open to involving patients during medical education. The moral dilemmas medical students face during the first years of their education impacts their professional development and may even affect the way they relate and talk freely to patients. (48) This may also progress the reform of medical education towards a focus on patient involvement, being better equipped to understand patient experiences and collaborate across disciplines. This includes supporting students in being open about AEs towards their fellow students by integrating it in the curriculum or during internships. As part of their internship students, as well as registrars, could attend M&MMs with patient involvement, or become involved in the organization, for example, by documenting meeting outcomes (e.g. learning points) in a PDCA cycle. It is important to include these aspects in medical education and provide the opportunity for students to engage with innovative patient-centered approaches.

Future perspectives in research

Every department should organize M&MMs with patient involvement as standard care. More research is needed to understand the differences in each context of each department. Monitoring different departments that implement the M&MM with patient involvement may provide us with a better understanding of contextual and general factors that are important for the

successful uptake of patient participation. Moreover, current trends show that healthcare delivery will increasingly have a digital component and that this will become the norm. Consequently, in research that focuses on M&MM in different departments the option to participate online needs to be taken into account.

Although our findings presented valuable insights on the importance of the patient's perspectives on AEs and their underlying causes, more research is needed to understand the benefits and challenges for patients who attend M&MMs. In our research, patients attended the M&MM once and were interviewed afterwards. However, when a patient is followed over a longer period of time, starting at the AE, we may understand the full benefits of attending an M&MM better. It may even impact patients' emotional and mental recovery, and how they perceive their care in the future.

A guidance with practice-based advice

Figure 4 shows a guidance with advice on which aspects are important when preparing a team or department for implementing patient involvement at the M&MM, including a guidance for the M&MM.

Figure 4. A guidance with practice-based advice for morbidity and mortality meeting with patients

Preparations for implementation

- Arrange top-down support for patient involvement at the M&MM (management/board)
- Discuss conditions with the patient board of the hospital (or patient organization) and the hospital legal- and quality teams
- Integrate a research project during the implementation process
- Be aware of assumptions and resistance towards patient involvement among healthcare professionals in your department and create time to reflect on them
- Invest in a safe environment within the team to be open about AEs with patients
- Start by inviting patienst who can easily communicate their experience and are keen to participate and be involved

Prior to the meeting

- Invite all healthcare professionals who were involved during the AE
- The case manager invites the patient
- Prepare the patient to use the video conference tool from their home
- Create sufficient time, resources and commitment of the core team to organize the M&MM with patient involvement

During the meeting

- A skilled moderator chairs the meeting (team member who is not involved in the AE)
- Healthcare professionals use comprehensible language and speak in a respectful tone
- The patient receives enough time to prepare and to share their experiences during the meeting, and is taken seriously with their experiential knowledge
- The patient is supported by their case manager
- During online meetings both the patient and the team are clearly visible and professionals are mindful of the lack of nonverbal language
- Meeting outcomes are well-documented, and repeated and reflected upon at the following meeting (include a Plan Do Check Act-cycle)
- The room has a U-shaped or round table and high quality audiovisual equipment

After the meeting

- The case manager talks to the patient and inquires about unresolved emotions or questions
- Provide the patient with a summary of the meeting outcomes after six months
- Start with practical adjustments to the M&MM and reflect on the first four meetings as a pilot
- Facilitate reflective practices at the end of each M&MM
- Encourage professionals to keep attending M&MMs

Concluding remarks

Based on our research we can suggest that, with the support of hospital management, each department and each healthcare professional has the practical capability to start implementing patient participation at the M&MM. One of the conditions is including a research institute or program alongside implementation to facilitate dialogue, reflection and continuous improvement. A team with one or more committed professionals and openness will push implementation further. It may even lead to transformed beliefs on what equality between patient and professional means, as well as what constitutes patient-centered and good care for healthcare professionals.

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chapter 8

summary samenvatting

Summary

In 2016, the gynecological oncology department of the Radboudumc began to invite patients (and their relatives) to the monthly morbidity and mortality meeting (M&MM), where the adverse event (AE) of the attending patient is discussed. The objective of this thesis is to study how the above patient-centered innovation can be (safely) implemented in clinical practice, and whether it encourages participants to learn, change behavior, and achieve improvements in care.

Chapter 1 introduces patient participation as a phenomenon and development in healthcare. The extent to which patients are involved in care processes has increased in recent decades. Consequently, the patient is increasingly seen as an important part of the improvement of care processes. We argue that the patient is an integrated part of quality of care. Interventions that can improve care require professionals to change and adopt a new way of working. In addition to technical or practical improvement steps, quality improvement is difficult to separate from a social innovation that requires different (social) relationships and ways of thinking. Quality improvement can thus be seen as a learning process. Patients who participate in care are part of healthcare delivery, and influence how healthcare professionals learn in the workplace – also referred to as 'workplace-based learning'. In surgical care, quality improvement can be looked at by reducing the number of AEs. Research in the Netherlands shows that AEs are frequently recorded, but that the number of preventable AEs and deaths did not decline in the periods 2011-2012 and 2015 -2016. M&MMs can play an important role in reducing the number of AEs and ultimately improve the quality of care. The meeting contains an educational role for healthcare professionals, as they discuss areas of learning and improvement. In terms of content, the M&MM focuses mainly on medical technical processes, but by discussing collaboration, communication and patient experiences, the quality of care can be improved on various levels. While scientific research describes how the M&MM can be improved with practical adaptations, patient participation or active involvement of patients during the M&MM has not yet been put forward as a step towards quality improvement. Involving patients could potentially impact on how healthcare professionals view patient-centered care and what constitutes good care, and reinforce workplace learning as a step towards quality improvement.

Providing openness and transparency to patients around AEs can be difficult, particularly how to do it appropriately as a healthcare professional. We examined the phenomenon of providing openness after an AE (disclosure) based on a literature review in **chapter 2**. The purpose of this study is to explore how to practice such disclosure communication, based on the perspectives of patients and healthcare professionals. Between September 2008 and October 2019, 2537 empirical studies focusing on this topic were found published in PubMed, Web of Science, and Psychinfo. Based on specific criteria, 23 relevant studies were selected and then analyzed. These showed that the strategies for communicating a disclosure exist on the level of interpersonal skills, organization, and supportive factors. Patients appreciate a disclosure with information tailored to their needs, and where there is room for dialogue. In this dialogue, concerns and emotions can be shared between patient and professional. We discuss that professionals would benefit from training in verbal and nonverbal communication after an AE. It is important to teach medical students how to embrace unexpected negative outcomes, or "mistakes," and learn from them. In this, an open (organizational) culture that encourages openness and open communication around an AE is important as the norm between professionals, and between the patient and the professional.

In **chapter 3**, the first eight M&MMs with patient participation in the gynecology department (gynecologic oncology) of the Radboudumc were evaluated. This exploratory study looked at how an M&MM can be organized with patient participation, and how professionals and patients can learn together from AEs. In-depth and semi-structured interviews were conducted with patients and healthcare professionals (specialists, nurses (case managers), registrars, residents). Observations were used to describe the context. The transcripts were analyzed by thematic analysis using the program Atlas.ti. Patients and professionals were generally positive about the innovative form of discussing AEs. The main reason for patients to participate in the discussion was to improve care for other patients in the future. Patients felt safe and secure to share their stories. In addition, it helped in the emotional processing of the AE and led to a better understanding of the course of the AE. It was very important that patients could bring someone to the meeting (e.g. family member, partner) and that the case manager (nurse) took the time to talk to the patient before and after the meeting. The biggest challenge for

professionals was to maintain the perceived quality of the M&MM in order to achieve medically substantive learning points and depth in the discussion - without harming the patient in doing so. This research resulted in five themes of importance to both patient and professional: the patient-doctor relationship, open communication, language, learning, and personal impact. Important conditions are a good patient-doctor relationship and openness between colleagues and to the patient. Attending multiple meetings leads to more openness, more confidence that it will not harm the patient, and a better balance in the use of comprehensive language and formulating learning points.

The Covid-19 pandemic accelerated adoption and increased communication through the digital medium. Patients' and professionals' experiences of M&MM via the video conferencing tool 'Lifesize' were evaluated through semi-structured interviews and observations.(**chapter 4**) The data collection and data analysis were based on the five themes from the M&MM where participants attended in person. All healthcare professionals had previous experience with the in-person (offline) meetings at the time of the online M&MM. The results show that all five themes remain relevant, but nonverbal communication and experience with the videoconferencing tool are important in this context. For patients and family, online participation is well established, as they have no travel time and felt comfortable sharing their experience through this medium. In the future, the gynecology department will continue to offer online participation in the M&MM as a common care.

Chapter 5 describes how the implementation of improvement points and suggested learning points arising from the M&MM can be better put into practice. How can a circular workflow optimize the follow-up of learning points, and which factors are important to achieve this? Practical components of the circular workflow include: an action list that follows the Plan-Do-Check-Act (PDCA) cycle, a "check" moment of the tasks at the next complication meeting, and regular monitoring of tasks. The participatory action research (PAR) approach was used in this research, in which the researcher is part of the organization as well as keeping track of the action list. All professionals who received a task on the action list were interviewed about their experience with the circular workflow and the reasons why they did or did not follow up on their task. A total of 10 M&MMs with 39 tasks were examined, which

resulted in 37 successfully implemented tasks that followed the PDCA cycle. The factors that are important in achieving this cycle are the organizational culture, motivation, commitment, skills and communication to mobilize employees. It can support professionals in implementing tasks if they work within an organizational culture where they can discuss openly and freely. Working within a team can also contribute to the implementation of tasks. An important point of discussion is whether professionals have learned enough from the AE in this form. The 'check' moment of the task focused on seeing if the task was completed or not. This raises the question whether this has sufficiently led to reflection and new insights that will actually result in professionals acting differently in the future.

In **chapter 6**, patient participation at the M&MM is investigated as a patient-centered innovation and seen as a potentially transformative learning process for professionals. The fact that professionals need to learn how patients can actively participate in their own care is often overlooked. Learning in practice in the workplace, also called "workplace-based learning," is a regular part of the training of medical professionals. Implementing patient participation in the M&MM can also be seen as workplace-based learning. This learning process at the M&MM was examined through various observations and secondary analysis of interview and observation transcripts (from the study described in chapter 3). A total of 25 interview transcripts, nine observations, and professional attendance at 17 M&MMs were included. In the grounded theory analysis, data were studied from a learning perspective to observe changes in perceptions, beliefs, or behaviors of professionals. The results show that: a) over time, a specific group of professionals has more experience than others and thus facilitates a learning environment for first-time professionals; b) a learning process occurs among professionals at three different levels. These three levels are explained on the basis of three clusters. Cluster 1 shows that healthcare professionals can involve patients in the discussion and establish a good relationship with trust. Professionals have already mastered the relevant skills on this level. In contrast, clusters 2 and 3 show that a deeper learning process has taken place. Cluster 2 refers to the openness that is needed to bring about change and learning. Cluster 3 describes how underlying beliefs, frames of reference, and assumptions changed after professionals attended M&MMs with patients for two years. In order to change and work or act with a patient-centered mindset as a professional, it is important to learn on a

deeper level. In the discussion, the concept of "double loop learning" is used to explain that a deeper level of learning can only occur when assumptions that do not match with the daily norm are questioned. This can happen through multiple experiences, as we have seen in the M&MM with patient participation, but also by working in an environment where the beliefs within a team have changed. Regular reflection, such as through interviews, is important. When professionals can learn at a level where they question their own norms regarding patient involvement in care, it may also be possible to apply a patient-centered approach in other situations or contexts where patients are involved.

In **chapter 7**, we begin to discuss resistance to patient involvement and present suggestions on how to overcome barriers with strategies for implementation. Both bottom up and top down strategies are relevant. Then we discuss what is needed to start implementing the M&MM with patient involvement from a learning perspective, taking workplace-based learning into account. Each hospital department will take a different amount of time and will need to go through different learning processes to implement patient involvement at the M&MM. Yet, we found that a team will always learn implicitly. Finally, we discuss future perspectives for practice and research, and present a guidance with practice-based advice for M&MMs with patient involvement. In conclusion, with the support of hospital management, each department and each healthcare professional has the practical capability to start implementing patient participation at the M&MM. One of the conditions is including a research institute or program alongside implementation to facilitate dialogue, reflection and continuous improvement. It may even lead to transformed beliefs on what equality between patient and professional means, as well as what constitutes patient-centered and good care for healthcare professionals.

Samenvatting

De afdeling gynaecologische oncologie van het Radboudumc is in 2016 gestart om de patiënt (en naasten) bij de complicatiebespreking uit te nodigen. Bij deze complicatiebespreking wordt de betreffende complicatie van de aanwezige patiënt zelf besproken.

Het doel van dit proefschrift is om te bestuderen hoe bovengenoemde patiëntgerichte innovatie (veilig) kan worden geïmplementeerd in de klinische praktijk, en of het de deelnemers aanzet tot leren, het gedrag te veranderen en om verbetering van zorg te bereiken.

In **hoofdstuk 1** worden patiëntparticipatie als fenomeen en ontwikkelingen omtrent patiëntparticipatie in de zorg geïntroduceerd. De mate waarin de patiënt wordt betrokken bij zorgprocessen is de laatste decennia toegenomen. De patiënt wordt dan ook steeds meer gezien als een belangrijk onderdeel in de verbetering van zorgprocessen. Wij stellen dat deze patiënt een integraal onderdeel is van de kwaliteit van zorg. Interventies die de zorg kunnen verbeteren vragen van professionals om te veranderen en een nieuwe manier van werken aan te nemen. Naast technische of praktische verbeterstappen, is een kwaliteitsverbetering moeilijk los te zien van een sociale innovatie. Om een innovatie of verbetertraject te laten slagen zijn namelijk andere (sociale) relaties en manieren van denken van belang, waardoor op het sociale niveau ook verandering plaatsvindt. Kwaliteitsverbetering kan zo gezien worden als een leerproces. Patiënten die participeren in de zorg zijn een onderdeel van het zorgproces, en hebben zodoende invloed op hoe zorgverleners leren op de werkplek – ook wel 'werkplek leren' genoemd. Een pijler van kwaliteitsverbetering in de chirurgische zorg is bijvoorbeeld een vermindering van complicaties. Onderzoek in Nederland laat zien dat complicaties veelvuldig worden geregistreerd, maar dat er in de periode 2015-2016 ten opzichte van 2011-2012 geen vermindering van vermijdbare complicaties en sterfte is opgetreden. Een complicatiebespreking kan een belangrijke rol spelen in het verlagen van het aantal complicaties en het uiteindelijk verbeteren van de kwaliteit van zorg. Deze bespreking, waarin leer- en verbeterpunten worden bediscussieerd, heeft een educatieve rol voor zorgprofessionals. De complicatiebespreking focust zich voornamelijk op de medisch technische processen, maar juist door het bespreekbaar maken van

samenwerking, communicatie en patiëntervaringen, kan de kwaliteit van zorg op verschillende niveaus verbeteren. Wetenschappelijk onderzoek beschrijft hoe de complicatiebespreking verbeterd kan worden met praktische aanpassingen, echter wordt patiëntparticipatie of actieve betrokkenheid van patiënten tijdens de complicatiebespreking vooralsnog niet aangedragen als stap tot kwaliteitsverbetering. Het betrekken van patiënten kan mogelijk impact hebben op hoe zorgverleners kijken naar patiëntgericht werken, naar wat goede zorg inhoudt en het leren op de werkplek versterken als stap naar kwaliteitsverbetering.

Het bieden van openheid en transparantie aan patiënten rondom complicaties kan een uitdaging zijn, met name de manier waarop je dit het beste kunt doen als zorgprofessional. Het fenomeen van openheid geven na een complicatie (disclosure) hebben we op basis van een literatuurstudie onderzocht in **hoofdstuk 2**. Het doel van deze studie is om na te gaan hoe je dergelijke disclosure communicatie kunt uitoefenen, gebaseerd op de perspectieven van patiënten en zorgverleners. Tussen september 2008 en oktober 2019 zijn 2537 empirische studies gevonden die zich richten op dit onderwerp gepubliceerd in PubMed, Web of Science en Psychinfo. Op basis van specifieke criteria zijn 23 relevante studies geselecteerd en vervolgens geanalyseerd. Hieruit bleek dat de strategieën om een disclosure te communiceren liggen op het niveau van interpersoonlijke vaardigheden, de organisatie en ondersteunende factoren. Patiënten waarderen een disclosure met informatie op maat die aansluit bij hun behoefte, en waarin ruimte is voor een dialoog. In een dialoog kunnen zorgen en emoties gedeeld worden tussen patiënt en professional. We bediscussiëren dat professionals baat hebben bij een training in verbale en non-verbale communicatie na een complicatie. Een belangrijk onderdeel daarvan is om medische studenten te leren hoe ze onverwachte negatieve resultaten, of fouten, kunnen omarmen en er van kunnen leren. Daarin is een open (organisatie) cultuur van belang, die openheid en open communicatie rondom een complicatie aanmoedigt als de norm tussen professionals onderling en tussen de patiënt en de professional.

In **hoofdstuk 3** zijn de eerste acht complicatiebesprekingen op de afdeling gynaecologische oncologie van het Radboudumc waarbij een patiënt heeft deelgenomen geëvalueerd. Deze exploratieve studie heeft gekeken naar hoe

een complicatiebespreking georganiseerd kan worden met patiëntparticipatie, en hoe professionals en patiënten samen kunnen leren van complicaties. Er zijn diepte- en semigestructureerde interviews gehouden met patiënten en zorgverleners (specialisten, verpleegkundigen (casemanagers), arts-assistenten). De observaties zijn gebruikt om de context te beschrijven. De transcripten zijn geanalyseerd door thematische analyse met behulp van het programma Atlas.ti. De patiënten en zorgverleners waren over het algemeen positief over de innovatieve vorm van het bespreken van complicaties. Voor de patiënten was de belangrijkste reden om deel te nemen aan de bespreking om de zorg te verbeteren voor andere patiënten in de toekomst. De patiënten voelden zich veilig en vertrouwd om hun verhaal te delen. Daarnaast heeft het geholpen in de emotionele verwerking van de complicatie én heeft het geleid tot meer begrip over het verloop. Het was erg belangrijk dat patiënten iemand (e.g. familielid, partner) mee konden nemen en dat de casemanager (verpleegkundige van de afdeling) vóór en na de bespreking de tijd nam om met de patiënt te praten. De grootste uitdaging lag voor zorgverleners bij het behoud van de ervaren kwaliteit van de complicatiebespreking, om te komen tot medisch inhoudelijke leerpunten en diepgang in de discussie, zonder daarin de patiënt te schaden. Dit onderzoek resulteerde in vijf thema's die van belang zijn voor zowel de patiënt als professional: de patiënt-arts relatie, open communicatie, taalgebruik, leren en persoonlijke impact. De voorwaarden die daarbij van belang zijn, is een goede patiënt-arts relatie en openheid naar elkaar als collega's en naar de patiënt. Het bijwonen van meerdere besprekingen leidt tot meer openheid, meer vertrouwen dat het de patiënt niet schaadt, en een betere balans in aangepast taalgebruik en het formuleren van leerpunten.

De COVID-19 pandemie zorgde voor een versnelde invoering en toename van het communiceren via het digitale medium. De ervaringen van patiënten en professionals met de complicatiebespreking via de videoconferentie tool 'Lifesize' zijn geëvalueerd door middel van semigestructureerde interviews en observaties (**hoofdstuk 4**). Deze dataverzameling en data-analyse zijn gebaseerd op de vijf thema's uit de complicatiebesprekingen waar deelnemers live aanwezig waren. Alle zorgprofessionals hadden ten tijde van de online complicatiebesprekingen reeds eerder ervaring opgedaan met de live (offline) gehouden meetings. De resultaten laten zien dat alle vijf thema's relevant blijven, maar dat non-verbale communicatie en ervaring met

de videoconferentie tool in deze context van belang zijn. Voor patiënten en familie is het online deelnemen goed te realiseren, doordat zij geen reistijd hebben en zich comfortabel voelden om via dit medium hun ervaringen te delen. De afdeling gynaecologische oncologie zal in de toekomst ook online deelname aan de complicatiebespreking blijven aanbieden als vast onderdeel van de zorg.

In **hoofdstuk 5** staat beschreven hoe de implementatie van verbeterpunten en voorgestelde leerpunten voortkomend uit de complicatiebespreking beter in de praktijk kunnen worden gebracht. Hoe kan een circulaire workflow de opvolging van leerpunten optimaliseren, en welke factoren zijn belangrijk zijn om dit te bereiken? Praktische onderdelen van de circulaire workflow zijn: een actielijst die de Plan-Do-Check-Act (PDCA)-cyclus volgt, een 'check' moment van de taken bij de volgende complicatiebespreking en het regelmatig monitoren van taken. Om dit te onderzoeken is de participatory action research (PAR) aanpak gebruikt, waarbij de onderzoeker onderdeel van de organisatie is én de actielijst met de checkmomenten bijhoudt. Alle professionals die een actiepunt hebben ontvangen zijn geïnterviewd over hun ervaring met de circulaire workflow en de redenen waarom zij wel of niet hun actiepunt hebben opgevolgd. In totaal zijn 10 complicatiebesprekingen met 39 actiepunten onderzocht, dat resulteerde in 37 succesvol geïmplementeerde actiepunten die de PDCA-cyclus hebben doorlopen. De factoren die van belang zijn om dit te bereiken zijn de organisatiecultuur, motivatie, toewijding, vaardigheden en communicatie om collega's te motiveren. Het kan professionals helpen om actiepunten uit te voeren als ze binnen een organisatiecultuur werken waarin zij open en vrij kunnen discussieren. Het werken binnen een team kan daar ook aan bijdragen. Een belangrijk discussiepunt is of professionals in deze vorm voldoende hebben geleerd van de complicatie. De 'check' van het actiepunt richtte zich op het kijken of de taak is volbracht. Dit roept de vraag op of dit voldoende heeft geleid tot reflectie en nieuwe inzichten waardoor professionals in de toekomst daadwerkelijk anders zullen handelen.

In **hoofdstuk 6** is patiëntparticipatie bij de complicatiebespreking als patiëntgerichte innovatie onderzocht en gezien als een potentieel transformatief leerproces voor professionals. Het feit dat professionals moeten leren hoe patiënten actief kunnen participeren in de zorg wordt vaak over het hoofd gezien. Leren in de praktijk en op de werkplek, ook "werkplek-leren"

genoemd, is een vast onderdeel van de training van medische professionals. Het implementeren van patiënt participatie bij de complicatiebespreking kan ook worden gezien als werkplek leren. Door diverse observaties en secundaire analyse van interview- en observatietranscripten (uit het onderzoek beschreven in hoofdstuk 3) is dit leerproces bij de complicatiebespreking onderzocht. In totaal zijn 25 interviewtranscripten, negen observaties en aanwezigheid van professionals bij 17 complicatiebesprekingen geïncludeerd. In de grounded theory analyse zijn data bestudeerd vanuit een leerperspectief om veranderingen in perceptie, overtuigingen of gedrag van professionals waar te nemen. De resultaten laten zien dat: a) over het verloop van tijd een specifieke groep professionals meer ervaring heeft dan anderen en zodoende een leeromgeving faciliteert voor professionals die voor de eerste keer deelnemen; b) een leerproces plaatsvindt bij professionals op drie verschillende niveaus. De drie niveaus zijn toegelicht op basis van drie clusters waarin verschillende thema's worden besproken. Cluster 1 laat zien dat zorgverleners patiënten kunnen betrekken in de bespreking en er een goede relatie met vertrouwen is opgebouwd. De relevante vaardigheden op dit niveau hadden professionals zich al eigen gemaakt. Cluster 2 en 3 laten daarentegen zien dat een dieper leerproces heeft plaatsgevonden. Cluster 2 refereert naar openheid die nodig is om tot verandering en leren te komen. Cluster 3 beschrijft welke onderliggende overtuigingen, referentiekaders en aannames zijn veranderd, nadat professionals gedurende twee jaar complicatiebesprekingen met patiënten hebben bijgewoond. Om als professional patiëntgericht te werken, handelen en denken, is het belangrijk dat er op een dieper niveau wordt geleerd. In de discussie is het concept double loop learning gebruikt om uit te leggen dat een dieper niveau van leren pas kan ontstaan wanneer aannames, die niet aansluiten bij de dagelijkse norm, bevraagd worden. Dit kan gebeuren als professionals meerdere keren een complicatiebespreking met patiëntparticipatie ervaren, maar ook als de onderliggende overtuigingen over patiëntparticipatie tijdens de complicatiebespreking binnen het team zijn veranderd. Regelmatig reflecteren, bijvoorbeeld door interviews, is daarbij belangrijk. Als men op dit niveau kan leren, zou men mogelijk ook in andere situaties of contexten, waarin patiënten betrokken worden, patiëntgericht kunnen handelen.

In **hoofdstuk 7** bediscussiëren we eerst de weerstand tegen patiëntparticipatie en presenteren we suggesties over hoe barrières kunnen worden overwonnen

met strategieën die de implementatie kunnen bevorderen. Zowel bottom-up als top-down strategieën zijn relevant. Daarna bespreken we wat nodig is om te beginnen met de implementatie van de complicatiebespreking met patiëntparticipatie vanuit een leerperspectief, rekening houdend met werkplekleren. Elke ziekenhuisafdeling zal een andere tijdsduur nodig hebben en verschillende leerprocessen moeten doorlopen om een deze complicatiebespreking te kunnen implementeren. Wij hebben ervaren dat een team altijd impliciet leert als zij een complicatiebespreking met patiëntparticipatie bijwonen. Tot slot bespreken we toekomstperspectieven voor de praktijk en onderzoek, en presenteren we een leidraad met praktijkgerichte adviezen voor complicatiebesprekingen met patiëntparticipatie. Concluderend, met de steun van het ziekenhuismanagement heeft elke afdeling en elke zorgprofessional de praktische mogelijkheden om de complicatiebespreking met patiëntparticipatie in te voeren. Eén van de voorwaarden is het opnemen van een onderzoeksinstituut of -programma naast het implementatieproces, om dialoog, reflectie en continue verbetering te vergemakkelijken. Het betrekken van patiënten bij de complicatiebespreking kan zelfs leiden tot hernieuwde opvattingen over wat gelijkheid tussen patiënt en professional betekent, en wat patiëntgerichte- en goede zorg voor zorgverleners inhoudt.

chapter 9

appendices

Data management statement

The research in this thesis complied with the Dutch law on medical research in humans (OPTIMA study). It also adhered to the Declaration of Helsinki on ethical principles for medical research involving human subjects. The local Medical Research Ethics Committee region Arnhem-Nijmegen (the Netherlands) approved the conduct of the research.

The digital data of the research project (**chapters 2-6**) is stored on the gynecology department's H-drive ((IMCfs049):H:\Onderzoek\ONCO-OPTIMA). Participation in the research project was voluntary and informed consent was provided prior to the start of the studies. The digital letters of informed consent, interview recordings and transcripts, and observation transcripts are stored on the previously mentioned H-drive. The paper letters of informed consent are stored in the department's archive (UTS Verkroost). The voice recordings were deleted from the recording device. All data was anonymized for analysis. The qualitative data in **chapters 3-6** was converted to Atlas.ti for analysis purposes and stored on the department's H-drive.

Data will be saved for 10 years after termination of the study (May 1st, 2021). This adjustment to the internal policy of the Radboudumc (15 years) was explicitly consolidated and approved in a file note (7-5-2019). Data of the research project is available upon reasonable request from the corresponding author.

Phd portfolio

Department: **Obstetrics & Gynecology**
PhD period: **01/04/2018 – 31/03/2021**
PhD Supervisor: **Prof. dr. J.A. de Hullu**
PhD Co-supervisors: **dr. P.L.M. Zusterzeel, Prof. dr. R.P.M.G. Hermens, dr. J.J. Koksma**

Training activities	Hours
Courses	
- RU - Designing a PhD research project (2018)	125.00
- Radboudumc - Introduction Day (2018)	6.00
- RIHS - Introduction course for PhD candidates (2018)	15.00
- PubMed introduction course (2018)	2.00
- Endnote workshop (2018)	2.00
- RU - Analytic Storytelling (2018)	20.00
- RU - Projectmanagement for PhD candidates (2019)	52.00
- RU - Scientific Writing for PhD candidates (2019)	96.00
- Workshop Atlas.ti (2019)	8.00
- RU - Effective Writing Strategies (2019)	75.00
- IMM - The Art of Presenting Science (2019)	36.00
- Radboudumc - Scientific integrity (2021)	20.00
Seminars	
- Peri-operatieve zorg: het voorkomen van complicaties (2018), attendee	7.00
- Kwaliteitsmiddag Gynaecologie (2019), oral presentation	4.00
- Radboud new Frontiers Symposium (2019), poster presentation	24.00
- ECHO session NHS Scotland (2022), oral presentation	2.00
Conferences	
- International forum on Quality & Safety in Healthcare (Amsterdam, NL), (2018), attendee	16.00 1.50
- Radboud Research Rounds (2018), oral presentation	8.00
- Gynaecongres (Amersfoort, NL) (2018), oral presentation	8.00
- Crafting the Future of Qualitative Health Research in a Changing World (London, UK) (2019), oral presentation	24.00
- BMJ International Forum on Quality and Safety in Healthcare (Copenhagen, DK) (2020), oral presentation	8.00
- Nursing & Oncology conference (Zurich, CH) (2021), oral presentation	
Other	
- RIHS PhD retreat (2018)	16.00
- Women's Cancer meeting (2019)	4.00
- Study group qualitative research (2019)	15.00
- Women's Cancer lunch meeting (2020)	9.00
- Research Community Medical Education (2021)	15.00
Teaching activities	
Lecturing	
- Lectures for gynaecologists, gynaecology residents and medical students (2019-2021)	10.00
Supervision of internships / other	
- Supervision student Medicine (2019)	56.00
Total	**684.50**

About the author

I was born in 1988 in Den Bosch and spent my childhood in Rosmalen alongside my parents and older brother. From a young age, I developed a fascination for health, women's issues and human behavior, as well as a passion for dancing and music.

After completing a Bachelor's degree in Cultural Anthropology and Development Sociology at Leiden University, my interest in reproductive health and people's health behavior grew during my research in Ghana on local belief systems related to health phenomena. This led me to pursue a Master's in Medical Anthropology and Sociology at the University of Amsterdam where I focused on people's risk perception during pregnancy and childbirth.

In the following years I worked as a (freelance) researcher on different projects in which I focused on health care experiences, and found myself enjoying qualitative research. For example, I evaluated a preconception care training program for individuals with intellectual disabilities, interviewed women who received gynecological treatment in Europe to include their perspectives in a curriculum for OBGYN trainees, and gained insight into the experiences of women and professionals with integrated childbirth care in the Netherlands. In addition, I volunteered for the Human Rights in Childbirth foundation and was trained as a doula, allowing me to pursue my interest in reproductive justice.

I applied for this PhD project to improve my overall research skills and combine my fascination for health issues with a patient-centered approach in healthcare. During my PhD, I co-founded the Dear Mama foundation to provide support for pregnant refugees and migrants. I spend my evenings training in a salsa showteam.

Currently, I am working as a senior researcher at Atria institute on gender equality and women's history in Amsterdam, taking on my next major challenge.

Publications

Academic publications

Myren, B.J., J.A. de Hullu, J.J. Koksma, M.E. Gelderblom, R.P.M.G. Hermens, P.L.M. Zusterzeel (2022) 'Implementation of areas for improvement resulting from morbidity and mortality meetings by using a cyclical workflow'
BMC Health Services Research.

Myren, B.J., P.L.M. Zusterzeel, J.A. de Hullu, J.A.M. Kremer, J.J. Koksma, 'Patient participation at the morbidity and mortality meeting: a transformative learning experience'
Social Science and Medicine - Qualitative Research In Health 2022; Dec;2:100105. doi:https://doi.org/10.1016/j.ssmqr.2022.100105

Myren, B.J., J.A. de Hullu, R.P.M.G. Hermens, J.J. Koksma, P.L.M. Zusterzeel 'Patient involvement via videoconference at the morbidity and mortality (M&M) meeting during COVID-19'
BMJ Open Quality 2022;11(1): e001691. doi:10.1136/bmjoq-2021-001691.

Myren, B.J., R.P.M.G. Hermens, J.J. Koksma, S. Bastiaans, J.A. de Hullu, P.L.M. Zusterzeel 'Openness to new perspectives created by patient participation at the morbidity and mortality meeting'
Patient Education and Counseling 2021; 104(2): 343-351.

Myren, B., J. de Hullu, S. Bastiaans, J. Koksma, R. Hermens, P. Zusterzeel 'Disclosing adverse events in clinical practice: The delicate act of being open'
Health communication 2022;Feb;37(2): 191-201. doi:10.1080/10410236.2020.1830550. Epub 2020 Oct 12.

den Ouden, J.E., R. The, B.J. Myren, D. Boss, W.J. van Driel, R.I. Lalisang, R.F. Kruitwagen, A.M. van Altena 'Development of a decision aid for primary treatment of patients with advanced-stage ovarian cancer'
International Journal of Gynecological Cancer 2020; Jun;30(6):837-844. doi:10.1136/ljgc-2019-001095.

Andel van, T., S. van Onselen, B. Myren, A. Towns, D. Quiroz '"The medicine from behind": The frequent use of enemas in western African traditional medicine'
Journal of Ethnopharmacology 2015; 174:637-643. DOI: 10.1016/j.jep.2015.06.040

Andel van, T., B. Myren, S. van Onselen 'Ghana's Herbal Market'
Journal of Ethnopharmacology 2012; 140(2):368-78. DOI: 10.1016/j.jep.2012.01.028.

Non academic publication

Myren, B., A. Oerlemans, P. Zusterzeel 'Patiënt schuift aan bij bespreken van complicaties' *Medisch Contact*
https://www.medischcontact.nl/nieuws/laatste-nieuws/nieuwsartikel/patient-schuift-aan-bij-bespreken-van-complicaties.htm

Dankwoord

Mijn dankbaarheid voor de afronding van dit proefschrift uit ik naar mijn team, familie, vrienden, collega's en ook naar alles wat dit proces mij heeft gebracht. Dankzij de afgelopen vijf jaar heb ik ontzettend veel kunnen leren en ben ik gegroeid als onderzoeker en kritische denker. Dit neem ik mee in al mijn toekomstige werk op persoonlijk en professioneel vlak.

Dit proefschrift had ik niet kunnen voltooien zonder het geduld en de aanhoudende steun die ik heb ontvangen van mijn team sinds mijn eerste weken in het Radboudumc. Aan het begin van mijn promotie was dr. Leon Massuger, destijds hoofd van de pijler gynaecologische oncologie, mijn promotor. Ik ben dankbaar voor zijn inzet en initiatief dat heeft geleid tot dit bijzondere onderzoeksproject. Daarnaast wil ik ook mijn mentor dr. Anne Speckens bedanken die tijdens onze jaarlijkse gesprekken de juiste vragen stelde. Hierdoor kon ik mijn eigen leerproces beter begrijpen en reflecteren op wat er bij mij speelde.

Petra Zusterzeel, jij was de eerste persoon waarmee ik contact had en ik ben blij dat we gedurende de hele tijd nauw hebben samengewerkt. We hadden altijd een gedeelde visie over het betrekken van patiënten, maar we moesten ook veel obstakels overwinnen om alles (zowel inhoudelijk als praktisch) in goede banen te leiden. En dat is ons gelukt. Dank je wel voor de uren die we telefonisch, online of aan je keukentafel hebben doorgebracht om tot oplossingen te komen en voor de kansen die je me hebt gegeven om te groeien als onderzoeker.

Joanne de Hullu, ik herinner me jou van mijn sollicitatiegesprek waarbij je doortastende praktische vragen stelde. Deze praktische en oplossingsgerichte houding heb je gedurende mijn hele proefschrift behouden, met goede feedback op mijn planning en altijd goed bereikbaar. Ik heb hier erg veel van geleerd, bedankt daarvoor.

Rosella Hermens, vanaf het begin was je betrokken bij het project en ik heb altijd gewaardeerd dat je er was. Ik heb je manier van feedback geven, je vriendelijke karakter en de momenten waarop ik bij je terecht kon met een kopje koffie en wat vragen, als heel prettig ervaren. Deze momenten gaven me weer goede energie om verder te werken.

Jur Koksma, een paar maanden na de start van het onderzoeksproject kwam je ons team versterken en daarmee was ons interdisciplinaire team compleet. Ik heb genoten van alle momenten waarop we konden filosoferen over de onderzoeken, verdieping zochten en waar mijn antropologische manier van kijken werd uitgedaagd. Het was een uitdagend leerproces waarin ik echt ben gegroeid, bedankt.

Fleur Lambermon en Doortje van den Dungen, wat fijn dat jullie mijn paranimfen zijn en aan mijn zijde staan om me te steunen op de dag van mijn verdediging.

Natuurlijk heb ik dit proefschrift niet af kunnen schrijven zonder de steun van mijn lieve vrienden en collega's (en combinaties daarvan). Door me even de zon in te slepen, samen te werken, biertjes te drinken, theetjes te drinken, mee te lezen, op onderzoekersweekend te gaan, frustraties te delen tijdens het treinreizen, heel veel uren salsa te dansen en shows te geven, te werken op de 7e in het OLVG (heerlijk op de zondag), of door gewoon een goede knuffel te geven, is dit me gelukt. Zelfs meedenken of sparren over mijn onderzoek was nooit te veel gevraagd. In alle eerlijkheid weet ik niet of ik genoeg pagina's zou hebben om de momenten te beschrijven die ik de afgelopen jaren met jullie heb gedeeld waar ik zo dankbaar voor ben. Ik hoop dat jullie weten hoe belangrijk dit voor me is geweest.

Ik wil ook mijn dankbaarheid uiten naar mijn ouders, Sven en Simone en mijn vriend Micha die me zijn blijven steunen om de tijd te nemen en alles goed af te ronden. Het heeft echt geholpen om te weten dat jullie vertrouwen hadden in het proces en alles wat daarbij komt kijken. Ik hou van jullie.

Als laatste wil ik nog even stilstaan bij de dag van mijn verdediging: 28 juni. Dit is de sterfdag van mijn opa die dan 20 jaar geleden is overleden. Mijn opa heeft me van jongs af aan veel geleerd over ondernemend en creatief in het leven staan, waar alles kan en niks te gek is. Bijzonder om op deze dag dit traject af te sluiten en dit ook te vieren met mijn oma, ooms, tantes, nichtjes en neefjes.

Veel liefs, Britt

Radboudumc
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