

# Optimizing quality of care in fracture patients at high risk of new fractures and patients with drug-resistant epilepsy eligible for resective brain surgery

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## **Impact**

This thesis contributed to patient-centeredness and efficiency of care for fracture patients at high risk of subsequent fractures and patients with drug-resistant epilepsy (DRE) undergoing brain surgery (resective epilepsy surgery, RES). This thesis highlights the importance of the many aspects needed to provide patient-centered and efficient care. In this section, we discuss the specific impact of the results of this thesis on society, health care, and research.

## **Background**

Health care focuses increasingly on patient-centeredness and efficiency of care, due to the increasing health and economic burden of diseases such as fragility fractures and drug-resistant epilepsy, the growing complexity of care for these diseases and the growing desire of patients to be involved in health decisions. The Dutch Integrated Healthcare Agreement 2023 (Integraal Zorgakkoord) [127] illustrates the need for patient-centeredness and cost-effectiveness and as essential parts of true evidence-based interventions. This thesis provided in Part I information on care utilization surrounding fracture liaison service (FLS) attendance of fracture patients and on (cost)-effectiveness of a multi-component adherence intervention (MCAI) among patients with a recent fracture that attend the FLS and are recommended to start anti-osteoporosis medication (AOM). Moreover, in Part II care utilization and clinical outcomes (quality of life and seizure frequency) were estimated in the first two years after resective brain surgery and in the period between the moment the patient with DRE enters the hospital with debut of epilepsy up until the patient undergoes surgery. The findings of this thesis may have direct and indirect impact society, healthcare and research.

## **Impact on society**

First, by taking a societal perspective for the cost-of-illness studies of both the RESQUE and ICON study, a striking need for support for (in)formal caregivers but also healthcare professionals outside the hospital was evident, such as speech therapy in the RESQUE or physiotherapy in the ICON study. This finding underlines the patients' need to be replaced for unpaid tasks and chores. Society as a whole seems to underestimate the value of these (temporary) care utilizations. Literature suggests caregivers contribute successfully to patient outcomes, leading to increased chance of reintegration into society, potentially minimizing wasteful resource utilization. Policy makers should consider to expand support for (in)formal caregivers of patients with acute or chronic disease that provide information on the aspects of the disease (and specific needs of patients) and study other needs to support them in their efforts.

Second, the unexpected adverse role of health literacy on AOM persistence of the MCAI challenges the principle of equitability of the Dutch healthcare system. Future policies should put more efforts in the development of health literacy responsive care. From an economic perspective, this will require additional costs, some of which can be paid off by gains in health. Moreover, limitations in health

literacy start very early in life and the numerous public health preventative (lifestyle) programs should ensure persons with limited health literacy are on board.

Third, we propose the MCAI should be implemented in all Dutch FLS. As the average persistence to OAM in the FLS of 53%, the MCAI will be more effective and cost-effective compared to usual care. Moreover, given the absence of incremental costs (-€16 per patient) of MCAI, costs of implementation will be limited to the education of the FLS nurse. Also, as society values patient satisfaction with care, the beneficial effect of MCAI on the patients experience with shared decision-making can contribute to satisfaction with health care in general. It should however be noted that the intervention requires some alterations for patients with limitations in health literacy before implementation.

Based on the advanced patient-centered outcomes and extensive resource utilization presented in the chapters of this thesis, more informed decisions could be made by decision makers, healthcare providers, ultimately improving access to care that is aligned with patient needs and allow for better use and allocation of resources within health care.

### **Impact on health care and patients**

Both studies aimed to improve quality of care for patients attending specialized care.

The newly developed patient decision aid (PDA) and the technique of motivational interviewing, as evaluated in the ICON study, are still being used by the FLS-nurse in the participating centers. This can be seen as an indirect proof of the value of MCAI for professionals when providing care. The limited time investment involved in MCAI for FLS nurses combined with the patients and nurses' positive experience with shared decision-making, stimulated us to plan the development of a training that informs FLS nurses on principles of shared decision-making and the use of the PDA in practice including skills to adapt the shared decision-making based on the (health literacy) needs of the patients. To further gain improvements in practice, peer-to-peer intervision should be implemented to allow for active reflection, discussion, and feedback through collective expertise. Importantly, as of May 25<sup>th</sup> 2024, the PDA falls under the Medical Devices EU Regulation as the PDA might influence the decision made in patient treatment. As a consequence, the PDA should be registered and receive a CE marking, so its safety and effectiveness for its intended use is recognized, which can facilitate the acceptance and adoption in the medical field. We hope the PDA will be recommended for use in the next osteoporosis management guideline.

The RESQUE study evaluated the clinical outcomes and economic impact of RES for patients with DRE. As the results demonstrate positive effects on patients' quality of life and seizure frequency when undergoing RES, the intervention should be considered earlier in the patient pathway. Based on

its proven clinical effectiveness and declined societal costs in the period after RES, earlier referral of these patients, particularly young patients, could significantly further enhance patient outcomes such as quality of life and benefit more from the effects of RES. Further long-term societal costs might decrease the burden on healthcare systems and (in)formal caregivers could be earlier alleviated.

Second, the results of the RESQUE study could further offer impact for healthcare professionals, namely neurosurgeons, neurologists, and nurse specialists as they conduct in-depth discussion on RES with the patients. These healthcare professionals could use the results on patient outcomes, including the quality-of-life sub-categories, to enhance patient-healthcare professional communication and be more specific what aspects would improve most after RES, thereby managing patient expectations more effectively before and after RES.

Overall, the results of this thesis demonstrate that patient-centered care can be enhanced through shared decision-making and create an evidence-based foundation for better patient-healthcare professional communication during clinical visits and further alignment with patients' needs and values when deciding on their treatment.

### **Impact on research**

The results of the ICON study have contributed to filling the gap of lacking longitudinal data on care utilization and costs surrounding the first FLS visit, and improvement of AOM persistence using a patient-centered intervention. As the MCAI was aimed for use in clinical practice, the intervention had to be conducted in a real-world setting to understand practical hurdles that would otherwise not be experienced. To avoid contamination of the of the usual care group by the principles of the MCAI provided by the same nurses, a quasi-experiment design (pre-post) was chosen. This expressed obstacles that are encountered when COVID-19 pandemic emerged and FLS was (temporarily) closed and when a new osteoporosis management guideline was introduced. Alternative design for complex interventions are still welcome. During the ICON, a Core Outcome Set for shared decision-making interventions was published. Future studies should measure all core outcome domains, including also knowledge of benefits and harms of each option and, alignment of chosen option with personal values. Most importantly, the effects of our intervention on different patient subgroups (i.e. health literacy) should stimulate researchers to further explore effects of complex interventions in relevant subgroups of patients. Specific for health literacy, research into health literacy responsive organizations should be studied. Clearly, patient-centered care is not a one-size-fits-all paradigm.

Second, the RESQUE study provides valuable insights into the possible limitations of generic quality of life instruments, providing valuable points of considerations for future research. The ceiling effect that was perceived in this study should be accommodated for in future research by either combining

the generic quality of life measure with a disease-specific quality of life measure, or incorporating a more comprehensive generic quality of life measure. This will allow for a deeper understanding of the patient's overall wellbeing and the impact of a specific disease, thereby allowing healthcare professionals to tailor patient-centered interventions more precisely.

Both studies have contributed to increased transparency on resource allocation within osteoporosis and epilepsy and identified some points of further research in the patient care in the Netherlands. The ICON study consolidates information on health literacy limitations in shared decision-making, potentially inspiring researchers to account for these differences in future research or delve deeper into the direct consequences of such differences on interventions applied to enhance patient-centered and efficient care. The RESQUE study provided a comprehensive overview from the moment the patient visits the hospital with debut of epilepsy up until two years after undergoing RES. These findings can stimulate scientific exploration and consequently progressing our understanding on the duration of referral to neurosurgery in epilepsy.

Overall, the chapters in this thesis combined health economics and patient-centered care and provided insights into common hurdles, challenges, and future prospective in health economic research for patient-centered care, which could ultimately inspire and guide future research in both areas of disease.

### **Dissemination of results**

The results of this thesis were presented at several international and national conferences including The World Conference of Osteoporosis, Osteoarthritis, and Musculoskeletal Diseases (WCO-IOF-ESCEO) 2024 in London, Kempenhaeghe annual symposium 2024, CAPHRI research day 2024, and the European Alliance of Associations for Rheumatology (EULAR) 2024 in Vienna. Workshops on shared decision-making are planned with the FLS nurses and presentatives of the Interdisciplinary Working group Osteoporosis (IWO). At the time of this thesis submission, four articles were publishes, one is under second review, and one is under submission.