

# Take a look through my eyes

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## Impact

*"As a district nurse, I've found the experienced quality measure as very pleasant because conversations took place with clients, informal caregivers, and formal caregivers. Through this measure, we were able to elaborate about the care in an accessible way from the client's perspective. By using the cards, topics come up that would not normally come up during an evaluation conversation."*

The aim of this dissertation was to 1) gain an understanding of the experienced quality in the home care setting, 2) acquire insight into current practices and needs of measuring experienced quality of home care, and 3) develop a novel qualitative experienced quality measure from a client's perspective for home care. This was done in collaboration with clients, informal caregivers, and formal caregivers from a relationship-centred care approach and focused on discovering improvements for the client's primary care process in home care. This chapter addresses the societal and scientific impact of this dissertation, thereby elaborating on both efforts made and those still needed to disseminate the findings.

### **Societal impact**

The results of this dissertation provide new insights into the client's experienced quality in home care; the needs of clients, informal caregivers, formal caregivers, and policy officers regarding current practices and desires with regard to experienced quality measures; and the development of a qualitative experienced quality measure from a client's perspective in Dutch home care. The relationships among clients, their informal caregivers, and their formal caregivers are important and should be included in measuring experienced quality from a client's perspective. Personal care experiences are shaped by dynamic interactions among clients, informal caregivers, and formal caregivers, requiring a different way of assessing these experiences. This can be achieved by using a more qualitative approach in measuring experienced quality in addition to quantitative measures. These types of measures are seen as fitting to care provided in the home care setting, since receiving care for extended periods allows for a more continuous evaluation in which multiple stakeholders can aid to understand and improve the experienced care quality. Using cards with pictograms can structure the evaluation and help in communicating the client's experiences compared to utilising standardised questionnaires. However, a qualitative measures approach requires a different way of analysing and interpreting the results. Compared to quantitative measurements and outcomes, this is seen as time-consuming

and labour-intensive in the long run and can have implications for use in the home care setting.<sup>1</sup> The use of qualitative measures such as the developed qualitative experienced quality measure should thus be seen as complementary to existing mandatory measures in Dutch home care, such as the PREM home care.<sup>2</sup> A reason for this is that the goal (micro-level) as well as the type of measure (qualitative, in-depth) and perspectives involved differ (clients, as well as informal caregivers and formal caregivers from a relationship-centred care perspective).

The developed measure was based on analyses of stakeholders' views on its feasibility in the home care setting (e.g., are the questions understandable and clearly framed) and usability in the existing care process (e.g., does it result in a sufficiently in-depth discussion of care experiences). Also, for the implementation of quality measures, it is important to attend to its robustness, as well as the fit with feasibility and usability criteria. Underlying motivational and other personal factors can be met by involving the key stakeholders from the start, since it is believed they are important to address when selecting suitable implementation strategies.<sup>3,4</sup> The goal, feasibility, and usability criteria served as a red line throughout the individual studies and were thus (to some degree) taken into account as *must haves* during the development of the measure. However, more work is needed in evaluating the developed experienced quality measure in a larger practice setting before it can be implemented in practice.

This dissertation and the studies conducted fit within a broader framework to develop an experienced quality measure in long-term care as supported in the Province of Limburg by the Limburg Meet knowledge programme and national advances in the Netherlands within various long-term care settings, such as nursing home care and disability care.<sup>5</sup> For the nursing home setting, a narrative method was developed in collecting and connecting residents' stories to provide information about the experienced quality of a care organisation.<sup>6</sup> For the disability care setting, several implementation strategies are being developed and evaluated for an existing narrative PREM.<sup>7</sup> The quality measure developed as a result of this dissertation is aimed at discovering concrete points of improvement to enhance the primary care process of individual home care clients. A first application of the developed measures shows that in most cases this was the result, although more insight is needed on outcomes if individual perspectives are analysed, communicated, and applied in practice. Team care meetings are often mentioned as a suitable place for discussing these outcomes with and among formal caregivers, although currently these meetings seem to focus mostly on discussing urgent matters. Activities undertaken to generate societal impact are listed under the dissemination of findings.

## Scientific impact

In addition to the societal impact, the studies in this dissertation have scientific impact for several reasons. First, this dissertation contributes to the scientific literature on the systematic approach towards the iterative development of a quality measure for home care. To our knowledge, this is the first attempt to apply the first three steps of the PROM cycle for the iterative development of a qualitative measure.<sup>8</sup> In the first step, the measurement's goal, key stakeholders, and setting were determined. Second, experienced quality was conceptualised by a theoretical framework and operationalised for the home care setting. Third, existing measures were selected and assessed using defined criteria for their goal, content validity, feasibility in setting, and usability in the care process. By following this approach, the goal in measuring experienced quality is placed above the actual measurement. During this process, attention was given to the measurement's content validity by determining which experienced quality domains to include. Moreover, a less conventional step is the application of requirements concerning the measurement's feasibility and usability during the development process. Although the developed measure adheres to the feasibility criteria, more insight is needed on its usability to integrate it within existing (evaluation) processes in home care.

Second, this dissertation contributes to a new view on experienced quality of long-term care as presented by the INDEXQUAL framework. INDEXQUAL presents the process of individual care experiences consisting of expectations before, interactions during, and an assessment of experiences afterwards. It adopts a relationship-centred care approach by acknowledging care relationships and following interactions among clients, informal caregivers, and formal caregivers as key-stakeholders in the caring context. Proposing quality as a dynamic process throughout the care process and acknowledging care relationships provide an additional layer to the previously dominant person-centred care approach in home care.

Third, existing methods from the user-centred design approach were adopted to allow for stakeholder participation as a central element throughout this dissertation for implementation in practice. An example was the Value Proposition Canvas, which served as a robust thematic framework during the analyses of stakeholders' needs.<sup>9</sup> Identifying and differentiating between key-stakeholders allowed to approach a single concept from multiple perspectives. However, during the study, this also brought dilemmas to light when individual perspectives did not align or even contradicted each other. An example was the dilemma of what needed to be done with the outcomes following the developed measure. In this case, managers and policy officers strived for a more systematic reporting, while formal caregivers stressed the importance of having no obligations in discussing or reporting outcomes in a given format within the care team. It is therefore important to

acknowledge the existence of these (sometimes conflicting) needs and be transparent about possible consequences on the following steps taken in the development of the measure. By doing so, both the scientific community and home care organisations can judge the trustworthiness of the developed qualitative experienced quality measure. There is a need for a more structured and transparent development process, since a number of qualitative measures in Dutch nursing care are not developed upon theoretical foundations nor provide available information regarding their (content) validity or usability for both clients and formal caregivers.<sup>10</sup> Although existing inventories are a first step towards making information on existing measures more easily accessible, progress is ongoing for the development of online databases providing a wide and more up-to-date overview of existing measures for multiple care settings.<sup>11,12</sup>

### **Dissemination of findings**

Throughout this project, various channels were used to disseminate the findings. This study was founded within the Brightlands Innovation Programme LIME (*Limburg Measures*), a programme that facilitates smarter measurement methods and more efficient data collection for better care and health. The programme strived in making connections between individual research projects and its outcomes with the needs of small business owners and governmental institutes such as municipalities and the Province of Limburg. The outcomes of individual studies were presented yearly in various settings, such as locally during the LIME symposia and internationally during the International Society of Quality of Life Research (ISOQOL) conference, the European Doctorate Conference of Nursing Sciences (EDCNS) conference to young academia, and an online Measuring Differently symposium with similar projects in both disability care and nursing home care. Local activities in participating home care organisations were organised, such as an online webinar during the *Kennispreuvenement* at Envida, where experiences with the developed experienced quality measure were shared with formal caregivers, managers, and policy officers. Although dissemination during additional symposia was planned, such as during the 2nd International Conference of the German Society of Nursing Science 2020 in Berlin, it was cancelled as a result of the COVID-19 pandemic.

All studies in this thesis were submitted to and/or published in international peer-review journals. Findings presented in this dissertation were integrated in existing education programmes. Lectures on care quality use the INDEXQUAL quality framework, and the developed experienced quality measure served as an example during interactive lectures for students in the health sciences bachelor's programme at Maastricht University. In addition, both bachelor's and master's students conducted literature reviews on factors related to experienced quality in long-term care and explored how the implementation of

the developed measure could be facilitated in home care for writing theses on these subjects.

The studies in this dissertation were imbedded in the research line of the Living Lab in Ageing and Long-Term Care, which disseminated findings widely through its network.<sup>13</sup> Additionally, individual care organisations shared items about both the project and the developed measure using their channels, such as an internal magazine distributed to employees, clients, and partners. A facts sheet and animation video was made to elaborate on the project and outcomes. Both a client council and a think tank of leading district nurses from the participating organisations were consulted during the individual studies. In addition, the outcomes of individual studies and research activities were presented to participating clients, informal caregivers, formal caregivers, and managers/policy officers during various group meetings throughout this dissertation. Various care organisations planned to continue in the further refinement and implementation of the developed measure within their home care teams.

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