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Roy Haex
Maastricht University

Theresa Thoma-Lürken PhD
Maastricht University

Anna J.H.M. Beurskens PhD
Maastricht University

Sandra M.G. Zwakhalen PhD, RN
Maastricht University

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Cover Page Footnote

Author contributions RH conducted the interviews and thinking aloud sessions, was moderator during focus group interviews, analyzed and interpreted the results and wrote the manuscript. TTL was second coder during analyses. TTL, SZ and SB were involved in the design of the study and critically revised the manuscript for important intellectual content. All authors read and approved the final manuscript and agree accountability for all aspects of the work, ensuring investigating and resolving questions related to the accuracy or integrity of any part of the work. Acknowledgments Authors would like to thank all clients, informal and formal caregivers, as well as the participating organizations for their valuable contributions to this study. Funding Statement This work was supported by the Brightlands Innovation Program LIME (Limburg Measures), a program that facilitates smarter measurements methods and more efficient data collection for better care and health, Province of Limburg, Zuyd University of applied sciences, Maastricht University, the Netherlands. This work is co-supported by the Living Lab in Ageing and Long-term Care. Ethics approval and consent to participate The study protocol was reviewed and approved by the medical ethics committee of Zuyderland and Zuyd University of Applied Sciences (METCZ20180003), who concluded that the study did not fall under the scope of the Medical Research Involving Human Subjects Act (WMO). Participants were informed verbally and in writing about the aim and expected burden of the study and gave their written informed consent to voluntarily participate and to have their conversations recorded. All information gathered was only used for this study and was processed separately from participants' identifiers to protect the privacy and confidentiality of the participants within this study. Declarations of interest: none This article is associated with the Policy & Measurement lens of The Beryl Institute Experience Framework (<https://www.theberylinstitute.org/ExperienceFramework>). You can access other resources related to this lens including additional PXJ articles here: http://bit.ly/PX_PolicyMeasure

Development of an experienced quality measure for clients, informal and formal caregivers in home care in the Netherlands: A participatory action research

Roy Haex, *Maastricht University, r.haex@maastrichtuniversity.nl*

Theresa Thoma-Lürken, PhD, *Maastricht University, t.thoma@maastrichtuniversity.nl*

Anna J.H.M. Beurskens, PhD, *Maastricht University, sandra.beurskens@maastrichtuniversity.nl*

Sandra M.G. Zwakhalen, PhD, RN, *Maastricht University, s.zwakhalen@maastrichtuniversity.nl*

Abstract

To optimise home care provision and to identify potential improvements in the care process, it is important to gain insight into the care experiences that influence care quality. The aim was to develop a qualitative experienced quality measure for home care in The Netherlands, facilitating conversations between clients and caregivers in generating possible points of improvement for the primary care process. A participatory action research design to develop the measure following three iterative cycles, using various data sources in evaluating requirements related to the goal, feasibility in care setting, and usability in the care process. The final design comprises an instruction meeting for district nurses and a structured approach to evaluate experienced quality with clients, informal caregivers, and formal caregivers. The measure encompasses cards to visually support communicating on experienced quality themes (e.g., personal needs and expectations), sub-themes (e.g., preferred way of communicating needs), exemplary questions, and a reporting sheet. The first evaluation gave indications of the measure results in formulating concrete points of improvement for the primary care process. This study indicates that the developed experienced quality measure seems promising relating to requirements for its goal, feasibility in the care setting, and usability in the care process. More insight is needed if and how improvements are communicated, documented, and followed-up in practice. In the next step, the measure should be extensively tested and evaluated in a more diverse sample (e.g., clients with dementia) for measuring experienced quality and reflecting on its outcomes.

Keywords

Experienced quality, home care, nursing, quality of care, long-term care, experience measures, measurement, client perspective, relationship-centred care

Introduction

In recent decades, there has been an increasing focus to deliver high-quality care services that are tailored to the needs of care recipients and facilitate ageing in place.¹⁻⁶ To optimise home care, it is important to gain insight into factors before, during, and after care that influence care quality.^{7,8} By gaining insight into care experiences, it is possible to know specifically where improvements in the care process are required.⁹ Patient-reported outcome measures (PROMs) are often used in measuring perceived outcomes on health and functional status, while care experiences as a measure of home care quality can be measured using patient-reported experience measures (PREMs).¹⁰⁻¹³ PREMs are seen as measurements of patients' perceptions of their experiences in the care process rather than the outcome of care, which can include close-ended as well as open-ended questions.^{14,15}

In 2018, a new national quality framework was released for home care nursing in the Netherlands.¹⁶ The framework

stated the importance of striving for good quality of care (QoC) by utilising measures to gain insight into the clients' experienced QoC and determine points of improvement for the primary care process. As a result, a PREM for Dutch home care was developed as a mandatory standardised questionnaire called 'PREM home care'.¹⁷ The goal of *PREM home care* is to measure experienced quality primary at the group (district) or organisational level.¹⁸ However, data on the group level does not always generate enough input for individual clients to improve their primary care process. In order to both assess and improve the QoC for individual clients, there is an increasing need to understand clients' care experiences using more qualitative methods, for example in-depth conversations with clients.^{9,19} Quality measures are extremely valuable in gaining more in-depth insight into care experiences, since they can be used as a source of rich and meaningful information on client experiences as well as the ongoing care process.²⁰⁻²² In addition to gaining insight into a client's perspective on person-centred care, the dynamic relationship between client and caregivers is increasingly

taken into account in sharing and understanding individual experiences in care provision.^{23,24} Discussing care experiences from a client’s perspective as well as both informal and formal caregivers thereby emphasises that all care relationships within the caring process are necessary in providing high QoC.²⁵⁻²⁸

If a measure ought to be used in daily practice, measures need to be useful.²⁹⁻³¹ Usefulness is seen as the degree to which a system (in our case, a measurement) is perceived by end-users (in our case, clients, informal and formal caregivers) as being able to use it to their advantage (e.g. assess and improve QoC).³² To enhance usefulness, a participatory and iterative design processes can stimulate the involvement of stakeholders (clients, informal and formal caregivers) throughout the development process by carefully planning actions, reflections, and revisions in short iterative cycles.^{33,34} During these cycles, the requirements to determine a measure’s usefulness in daily practice are applied by evaluating its goal, feasibility in the setting, and usability in the care process (see Figure 1).

The goal describes what the measure would like to accomplish and what is needed and is seen as the degree that measure’s content and following outcomes can be used by the users (clients, informal and formal caregiver). The feasibility of a system describes how well the users can use its functionalities and is seen as the degree a measure can be appropriately applied by those involved. The usability of the measure determines the fit with the ongoing care process. It provides insight into when one should apply the measure, who should evaluate, how to evaluate, what motivates one to evaluate, and what to do with the outcomes. The measure’s feasibility and usability are both constructs used to evaluate products or services, exploring the ease of use and a good fit for people using it as characteristics of the product.^{35,36} Previous studies have found that criteria related to a measure’s usefulness, such as having sound usability, is an accurate predictor of

Although a number of qualitative experienced quality measures exist in other long-term care settings (e.g. nursing home care and disability care), it is often unclear if and how these measures provide input for the primary care process in home care, thereby being part of a total system to consciously improve quality.³⁸ Previous work in identifying existing experience quality measures for home care resulted in the identification of four potential promising measures.³⁹ These measure were developed for either the nursing home care or disability care setting.⁴⁰⁻⁴³ A shortcoming of these measures for application in home care is that they were not developed specifically for the home care setting and therefore required the adaptation of its content in order to be useful. However, these measures served as a starting point for the current study. It was therefore needed to further develop these promising qualitative measures for home care that facilitate conversations between care providers and receivers to generate useful outcomes for the primary care process.

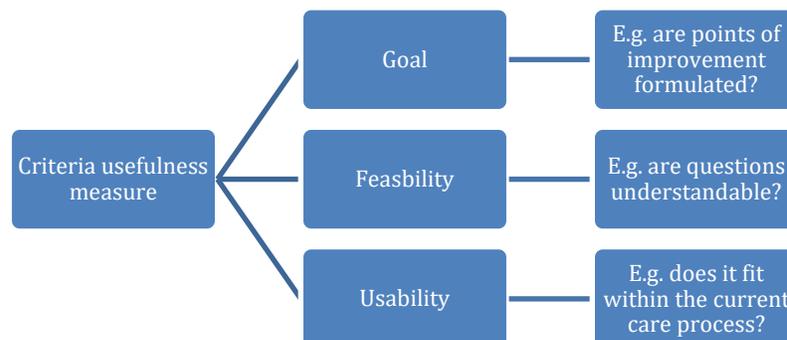
This study was set up to develop a qualitative experienced quality measure specifically for home care in the Netherlands, which could assess experiences of care and give input into improving the client’s primary care process. The following questions were the focal point throughout the development process: 1) To what extent do end-users perceive the measure as supportive for the goal of providing input for improving the client’s primary care process in home care; 2) How far is the measure perceived as feasible to measure experienced quality in home care; 3) How far is the measure perceived as usable within the current caregiving process in home care.

Methods

Study design

A participatory action research (PAR) design was used to develop the qualitative experienced quality measure for home care. By adopting the key principles of PAR, a

Figure 1. Overview of criteria determining a useful measure



stakeholders’ behavioural intention to apply it, e.g. in home care practice.³⁷

Box 1. Four phases of PAR

1. Plan (revision of developed measure's prototypes)
2. Act and observe (testing the measure's prototype)
3. Reflect (evaluation of prototype on goal, feasibility in context and usability in care process)
4. Revise (construct list of requirements)

measure can be developed in an iterative approach and the involvement of key-stakeholders (clients, informal and formal caregivers) can be incorporated throughout the process.³³ PAR is defined as 'an approach employed by practitioners for improving practice as part of the process of change' and it is defined as 'a continuous learning process in which the researcher learns and also shares the newly generated knowledge with those who may benefit from it' (Koshy, Koshy & Waterman, 2010, p. 9). PAR is conducted in four phases (see Box 1).

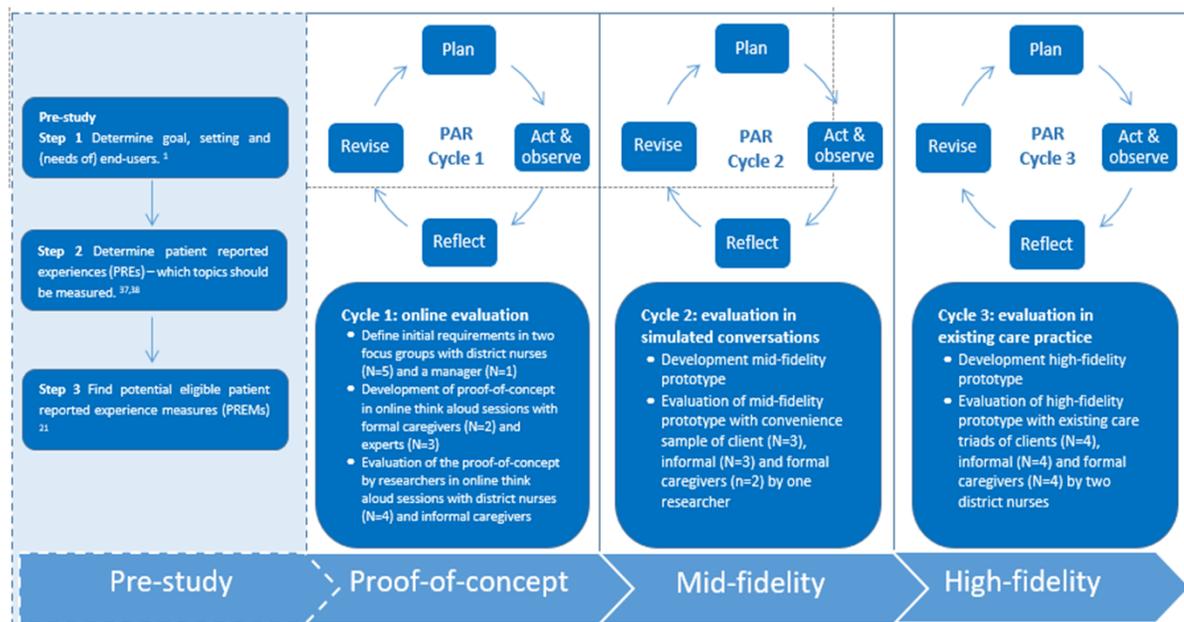
Data collection process and participants

The study took place between April 2020 and February 2021. Since of the COVID-19 pandemic started in 2020, most data collection activities were conducted online. For other data collection methods, appropriate measures were taken ensuring that COVID-19 prevention guidelines were correctly applied, such as maintaining a minimum physical distance, no physical contact, and thorough cleaning of the handled materials. The development of the measure consisted of three iterative participatory action cycles, each consisting of the four PAR phases (see Figure 2). Within these cycles, various data sources were used to evaluate the requirements related to the goal, feasibility, and usability of the experienced quality measure. Participants of this study, different for each participatory action cycle, were recruited

from a publicly funded, team-based home care organisation in the southern part of the Netherlands.

This study used 3 sources of data to evaluate the requirements related to the goal, feasibility, and usability of the experienced quality measure, specifically: 1) Focus group interviews with district nurses and a manager in which preferences are shared regarding existing measures and to determine the requirements related to the goal, feasibility, and usability. 2) Thinking aloud sessions with clients, informal caregivers, formal caregivers, and experts in the field of communication in long-term care in which the evaluation is simulated/conducted based on the measure and corresponding questions. 3) Semi-structured individual interviews related to the goal, feasibility, and usability of the measure with formal caregivers, informal caregivers, and clients. The thinking aloud sessions as well as the semi-structured interviews were preferably conducted individually with participants. If necessary, the informal caregiver could support the client in the interview but was asked to not actively engage in the conversation (e.g., in case a client had trouble speaking clearly). The thinking aloud sessions, semi-structured individual interviews, and focus group interviews were conducted online, by telephone or at a location preferred by the participant. The planned duration of the thinking aloud

Figure 2. Overview of steps taken throughout development process



combined with the semi-structured individual interviews was one hour. Throughout this study, participants were recruited by means of convenience sampling, although some minimal recruitment criteria were stated such as having experience with (either providing or receiving) home care.

Cycle 1. Online evaluation of the proof-of-concept

In the plan phase of the first iteration, four existing qualitative experienced quality measures were presented in two focus group meetings with five district nurses and one manager appointed by the two participating home care organisations. Participants were asked to reflect on the goal, the feasibility in the setting and usability in the care process, resulting in formulating individual requirements for each of these categories. Requirements were prioritised as *must haves* and *nice to haves* based on the principles of the MoSCoW method.⁴⁴ Requirements were classified as a *must have* if incorporating them were seen as essential for developing the experienced quality measure (see Box 2).

Requirements not adhering to these criteria were classified as *nice to have*, thereby preferable by stakeholders but not essential. Based on these requirements, individual components of the measure (themes, pictogram sketches, and questions) were evaluated by three colleague researchers/experts in the field of long-term care and two district nurses. In an online presentation, the individual components were presented, and feedback was solicited on these components. This led to initial adjustments concerning the formulation of individual questions and the use of pictograms depicting individual themes, resulting in the development of the measure's proof-of-concept.

Next, the proof-of-concept was individually presented in online think aloud sessions to four district nurses and two informal caregivers that were recruited by means of snowball sampling. Participants received a general explanation of the measure by presenting a case description, elaborating on its goal and requirements on the feasibility in the setting and usability in the care process. Then, the measure was presented by going through the individual themes and corresponding questions by screen sharing interactive slides in Microsoft PowerPoint. Participants were asked to think aloud during this phase.⁴⁵ This was followed by a semi-structured interview in which questions were asked concerning the requirements (goal, feasibility in the setting, and usability in the care process, Table 3). Notes were taken during the online conversation, which were complemented by watching the video recordings, resulting in summaries of

individual interviews. The cycle was finalised by formulating the list of requirements.

Cycle 2. Evaluation of the mid-fidelity prototype in simulated conversations

Based on the list of requirements, the mid-fidelity prototype was developed. The mid-fidelity prototype of the measure was applied during six simulated evaluations conducted by one researcher (RH). A convenience sample consisting of three clients, three informal caregivers, and two formal caregivers first received a general explanation of the measure by presenting a case description. This case description explained a fictional scenario of a client's home care situation, the role of the informal caregiver, and contextual information on applying the developed measure by the district nurse. Next, the simulated conversation took place where themes were presented on three cards and participants were asked to select one. This resulted in a structured conversation based on the corresponding sub-themes, displayed on the back of the selected card.

Based on the answers of the participants, additional elaborative questions were asked if they seemed relevant by the assessor. Subsequently, the card and corresponding questions related to care outcomes were discussed. The conversation concluded by summarising the discussed theme/sub-themes and outcomes. Finally, a semi-structured interview was conducted in which questions were asked concerning the measure's requirements. Notes were taken during the conversations that were complemented by listening back to audio recordings, resulting in summaries of individual interviews. Again, the cycle resulted in formulating the list of requirements.

Cycle 3. Evaluation of the high-fidelity prototype in care setting

Based on the list of requirements of cycle 2, the high-fidelity prototype of the measure was developed. During cycle 3, this was evaluated by two district nurses appointed by one participating care organisation. As a result of the response during the first and second cycles, instructions were developed. The list of requirements following cycles one and two resulted in formulating individual elements of the instructions. The instructions explain the utilisation of the developed measure and were provided online to participating district nurses as assessors in the third cycle; this lasted around 75 minutes. The instructions had the following structure: first the aim of the study was described, followed by the goal of the measurement, a general definition of experienced quality, and a concise description of the preceding development steps to explain ongoing development study to the participating district

Box 2. Applied criteria determining *must haves*, based on the following criteria:

1. Mentioned by at least 50% of the participants and/or;
2. Mentioned at least once in both group meetings and/or;
3. Clearly framed as a hard judgement/urgency by the participant (e.g., it is essential to have this).

nurses. Next, the flow of the measurement in the care process was presented by an animation made in Vyond. Third, the developed qualitative measurement was presented stepwise as actions needed before, during, and after use. Fourth, some dos and don'ts concerning important interviews skills were presented (including open versus closed questioning, appreciating inquiry, and use of silences). A short summary concluded the session after which the district nurses received the required materials and were asked to do a 'dry-run' with a participant.

Home care clients, their informal caregiver, and the best-informed formal caregiver providing the most care (in time) were recruited in existing care triads. Home care clients were eligible to participate if they were receiving long-term home care based on at least one chronic condition, were currently receiving informal care and were both mentally and physically able to participate according to their district nurse. Eligible clients were selected and contacted by their district nurse and received written information explaining the study's purpose. The district nurse asked participating clients for permission before contacting their informal and formal caregiver. The measure was conducted one-on-one by the district nurses with individual clients, as well as their informal and formal caregivers. With the permission of the participants, audio recordings were made of the conversations between the district nurse and the client/informal caregiver /formal caregiver. These audio recordings were used to check if the measure was conducted as intended, an aspect of its feasibility in the setting. During the conversation, district nurses could write the select theme, discussed sub-themes, and both outcomes and care arrangements on a reporting sheet. Afterwards, clients, informal caregivers, formal caregivers, and assessors of the measure (district nurses) were asked to participate in a telephone interview concerning the measure's requirements, conducted by a member of the research team (**blinded for peer review**).

Data analysis

For the data collected throughout this study, the principles of directed content analyses were followed.⁴⁶ Summaries of the conversations in cycle one, two, and three were deductively analysed by using the requirements categories (goals, feasibility in the setting, and usability in the care process) and underlying requirements as a thematic framework (see Table 3).⁴⁶ This resulted in constructing a list of requirements, resulting in immediate adjustments to the measure if there was a clear consensus between participants (e.g., reformulating questions, using different icons depicting specific themes), elements of the measure that needed further clarification (e.g. explanation in the instructions for the measure), or optional adjustments if no consensus was found between participants (e.g., preferences on how outcomes should be documented). For the optional adjustments, these points were laid out to

participants in the following cycle. This was followed by developing a new version of the measure's prototype.

Ethical considerations

The study protocol was reviewed and approved by the medical ethics committee of Zuyderland and Zuyd University of Applied Sciences (METCZ20180003), who concluded that the study did not fall under the scope of the Medical Research Involving Human Subjects Act (WMO). Participants were informed about the aim and expected burden of the study and gave their written informed consent to voluntarily participate and to have their conversations recorded. During the first cycle, participants reconfirmed their willingness to participate by providing online oral consent to the study as well as the video recording of the conversations. For cycle two and three, participants gave written consent during physical conversations in which the measure was conducted, and audio recordings were made. District nurses consulted their clients, formal caregivers, and informal caregivers before providing contact information to the research team for the telephone interviews. Afterwards, participants were asked to provide demographic information. All information gathered was used for only this study and was processed separately from participants' identifiers to protect the privacy and confidentiality of the participants of this study.

Results

Participants

A total of 39 participants took part in this study, of which 17 participated in the first cycle, 8 in the second, and 15 in the third cycle. Table 1 provides information about the demographics of the participants throughout the study.

Development process

First, requirements were defined for the development of the proof-of-concept (see Table 2). Next, the results throughout the development process were presented and categorised by the individual research questions in which participants reflected on the defined requirements following the first cycle.

Goal for improving the primary care process

Throughout the development, most participants expected that the developed measure would be supportive towards providing input for improving the primary care processes. In the third cycle, six out of the 13 evaluations discussed concrete outcomes, varying from improving communication between care providers to changing care planning and evaluating previously discussed points of improvements. All indicated that the measure and following conversation were a positive activity for the ongoing care process, even when it did not lead to concrete improvements in the care process. The reasons were that the measure would allow participants to know

Table 1. Demographics

		N	Sex (male, female)	Median age (range)
Cycle 1: development & evaluation of proof-of-concept (N = 17)				
Role	Colleague researchers/communication experts	5	5 females	28 (14)
	District nurses	9	9 females	29 (14)
	Manager	1	1 female	54
	Informal caregivers	2	2 females	35.5 (13)
Cycle 2: evaluation of mid-fidelity prototype (N = 8)				
Role	Clients	3	2 male, 1 female	67 (28)
	Informal caregivers	3	1 male, 2 females	65 (19)
	Formal caregivers	2	2 females	64 (2)
Cycle 3: evaluation of high-fidelity prototype (N = 15)				
Role	Clients	5	1 male, 4 females	78 (14)
	Informal caregivers	4	3 male, 1 female	77 (20)
	Formal caregivers	4	4 females	49 (29)
	District nurses	2	2 females	34 (12)

each other better, possible leading to improvements in care provision by understanding a client's previous way of living. In addition, the measure was seen as a structured approach to defining concrete points of improvement, for which participants currently lacked alternative measures. However, some mentioned that the measure would be less suited to urgent matters that should be discussed immediately (e.g., by discussing with direct caregivers or addressing it over the phone).

Feasibility in the home care setting

Insight was gained on the requirement of using *fitting and clear pictograms* on the card to visually communicate individual questions in a manageable and accessible way. The developed cards allowed participants to pick them up and read them by themselves, providing participants with a clear structure throughout the conversation. Most

participants indicated that the pictograms on the card were helpful as a visual aid, easy to understand and a fun way to have a conversation with each other. In doing so, it aided both the assessor and respondent to keep focus on the selecting theme/sub-theme while discussing. In visually communicating individual themes on each card, photographs were seen as more personal, only suitable in specific care processes and therefore more difficult in contrast to using pictograms depicting the themes.

With regard to the requirement of *conducting the measure within a limited time frame of five to 10 minutes*, most participants thought this to be unrealistic beforehand. The duration of the simulated conversations in the second cycle was 21 minutes on average. Although some informal caregivers and clients thought it would be possible by preparing for the conversation, others saw 20 minutes as

Table 2. Overview of determined requirements (must haves)

	Requirements (must haves)
Content (goal)	<ul style="list-style-type: none"> ▪ Must provide input for improving the primary care process
Feasibility (in setting)	<ul style="list-style-type: none"> ▪ Must have clear pictograms fitting the setting ▪ Must be able to conduct it within a limited time frame (5-10 min.) ▪ Must be understandable with clearly framed questions ▪ Questions must be clearly related to care provided in the home ▪ Measure must be conducted by an assessor as intended
Usability (in care process)	<ul style="list-style-type: none"> ▪ Must be administered at least twice a year or more often if needed ▪ Must have questions related to the current care relationship with the district nurse ▪ Must be conducted by the district nurse within their own care team or neighbouring care team ▪ Must result in a sufficiently in-depth discussion of care experiences facilitated by the assessor ▪ Must have an appreciative inquiry fitting the home care setting ▪ Must result in concrete outcomes reported in the care plan or communicated to the care team

more realistic. Especially, care providers worried that, by limiting the time to 10 minutes, they would come across as business-like and worried that clients would not feel heard. In the third cycle, participants experienced sufficient time in discussing the care experiences. Based on the length of the audio-recording, the duration of assessing the experience measure varied between 8 to 13 minutes. However, a difference in recorded and guessed/reported duration was found for clients and informal caregivers during the telephone interviews (45-60 minutes). The district nurses explained this difference as result of extra time needed in explaining the measure, filling in the informed consent, and demographics, as well as having a social talk.

Relating to the requirement of having *understandable and clearly framed questions*, participants throughout the study gave suggestions on improving the formulation of individual questions. An example was that including both open and close-ended questions would make the measure more accessible, although stating the need to ask for elaboration in responses using close-ended questions. In addition, a preference was given to highlight vital words (e.g., sub-themes) to recognise the focal topic in each question. The formulated questions during the third cycle were seen as a ‘nice average’, i.e., not too difficult or too easy. An important note is that it was seen as a necessity by formal caregivers to reframe questions based on a client’s communication skills and societal background. Some formal caregivers mentioned that they found it difficult in answering the questions from a client’s perspective, and thereby missed discussing their own perspective. The district nurses as assessors found it somewhat difficult to reformulate the questions asked to informal and formal caregivers, since most questions were formulated from a client’s perspective (e.g., how does your client experience communication with formal caregivers?). Another point of attention was that most clients found it difficult to formulate concrete improvements when being asked directly, although these were often formulated in a later stage during the conversation. Furthermore, for the requirement that *questions must be clearly related to care provided in the home* (nursing and personal care), all participants agreed that this was indeed the case and not related to e.g., domiciliary care or care provided by a GP.

Last, for the requirement *if the measure was conducted by assessor as intended* for the third cycle. The questions were either formulated openly or district nurses kept asking in the case of a closed question. In some cases, the questions were formulated suggestively (‘I see that quite a high number of care providers do visit you...’), which occurred mostly during conversations with formal caregivers. During these conversations, input from the conversations with a client or informal caregiver was sometimes used by the district nurses as a confirmation to the formal caregiver’s response (‘problems with her bandages...this is

indeed something I also heard from the client’). In 10 of 13 conversations, the theme ‘dealing with caregivers’ was selected and a three to four in-depth questions were asked. Answers were summarised thoroughly during the conversations, and a more general summary was provided afterwards.

Usability in the home care process

For the requirement of *administering the measure at least twice a year or more if needed*, participants throughout the development cycle indicate this to be a recommendable average, although they address the importance of having the flexibility to base the onset on both the client’s condition and care complexity. For urgent matters, most clients and informal caregivers indicated that they would contact the organisation more directly (e.g., by phone or in a discussion with direct caregivers). For the requirement that *questions are appropriate and related to the current care relationship with the district nurse*, clients, and informal caregivers in the third cycle found it pleasant to have the district nurses conduct the measure, because this was often an already known person. Both clients and informal caregivers often mentioned being unaware of the district nurse’s role within the care team, although trust, being a care provider, and being open-minded were mentioned as important factors for conducting these conversations. However, formal caregivers mentioned that it should be the responsibility of the whole care team to conduct the measure. This was related to the requirement of *conducting the measurement by district nurses within their own care team or neighbouring care team*. Although the district nurses were seen to be suitable persons for conducting the developed measure, formal caregivers preferred to keep the evaluation (both the conducting as well as the outcomes) mostly within their care team since the conversations were perceived as ‘personal’. A possible reason for this was that, in one case, a formal caregiver felt put on spot by the district nurse by checking how well she knew the client and thereby missed discussing her own perspective.

For the requirement of having a *sufficiently in-depth conversation*, the findings showed that the measure allowed participants in cycles two and three to have a ‘good conversation’ and communicate a broad range of experienced quality topics. The in-depth questions were seen as necessary in formulating concrete points of improvement. In the third cycle, participants indicated that everything was sufficiently thoroughly discussed, although sometimes requiring an effort from the district nurse to keep asking on a specific subject. In line with this, did the district nurses indicate that it requires a minimal level of communication skills in conducting conversations, e.g., to address emotional needs. For them, this was a reason to limit the utilisation of the measure throughout the whole care team to care providers with sufficient communication skills. For the requirement of *appreciate inquiry fitting with the home care setting*, participants throughout development were

Box 3. The key characteristics of the developed qualitative measure were:

- Assess experienced quality in home care as defined by the INDEXQUAL framework⁴⁸
- Include care triads consisting of clients, informal caregivers, and formal caregivers from a relationship-centred care approach (client decides)
- Adopt principles of an appreciative inquiry approach, stimulate to perceive evaluating as a positive element in the care process
- Allows individual stakeholders in the care triad to tailor assessments by selecting relevant topics, inclusive by offering visual support
- Provide both assessors and evaluated stakeholders a clear structure and content in assessing experienced quality, supported by exemplary questions and visual support in communicating topics

mostly unaware of this approach, although it was seen as fitting the home care setting. Moreover, participants still experienced sufficient room in also discussing more negative care experiences. The district nurses in the third cycle recognised the approach, since this was in line with the general policy practices adopted from a program called Positive Healthcare (Dutch: Positieve Gezondheid) throughout their organisation.⁴⁷

For the requirement that the measure should *result in formulating concrete outcomes*, the current care plan was often mentioned as a suitable location for reporting the outcomes related to previously set care goals. For other outcomes or insight provided, most formal caregivers wanted to be flexible in deciding how to communicate this within the care team before reporting back to individual clients. For the third cycle, participants mentioned that the outcomes were reported in the existing care plan or afterwards directly communicated to the direct caregiver in a meeting. The reporting sheet was welcomed and used by one district nurse, but the other made no use of it. The reason for this was that the conversations involved her own clients, and she therefore had no difficulties in remembering the discussed topics, outcomes, or care agreements made. Finally, district nurses noted that the order of applying the measure in the third cycle occurred randomly, although all formal caregivers were included last. Although they responded that for clients with complex care needs or who communicated a negative care experience, they would most likely want to include the formal caregiver's perspective first. The reason for this was to know what is going and 'be prepared' for the conversation with this specific client. Next, the instructions and developed experienced quality measure were presented.

Developed qualitative experienced quality measure

The key characteristics of the developed measurement can be found in Box 3 and more detailed information on the contents of the measure can be found in Table 3.

Discussion

This participatory action study followed three cycles describing the steps and rationales undertaken in developing a qualitative experienced quality measure aimed at improving the client's primary care process in home care. The final design comprises an instruction meeting for district nurses and a structured approach to evaluate experienced quality as defined in the INDEXQUAL framework with clients, informal caregivers, and formal caregivers. The measure encompasses a set of cards to visually support to communicate context-specific experienced quality themes (e.g., personal needs and expectations), sub-themes (e.g., preferred way of communicating care needs), corresponding exemplary questions, and a reporting sheet. Both the content as well as the structure of the measure are based on insights gathered from stakeholders participating in this and previous studies.

The goal of the developed measure was seen as focused on discovering concrete points of improvement for the client's long care process, although seen as less suited for discussing urgent matters. For the requirements on its feasibility in the home care setting, the measure appears to have a helpful structure in visually communicating experienced quality themes on the developed cards, is seen as manageable to be conducted in around 10 minutes, and the formulated questions are seen as both clear and fitting to respondents. However, reformulating questions based on the respondent's communication skills and background was seen as a necessity, as well as increased attention for assessors to decrease the use of suggestive questions within the subsequent conversations in a care triad. As for the first results regarding usability in the care process, bi-annual administration was seen a good average for the measure, although the needed flexibility of using it more frequent for clients with a more complex care situation was addressed. Both the measure and individual questions seem to fit the current care relationships between respondents and district nurse, although follow-up questions are needed to have an in-depth discussion towards formulating concrete points for improvement. The documentations of the outcomes in existing care

Table 3. Individual themes, pictograms and questions of developed final design

Theme	Pictogram	Main questions*	In-depth questions (<i>sub-themes</i>)*
Personal needs and care expectations		<ul style="list-style-type: none"> ○ How well does the care meet your needs? ○ How well does the care meet your expectations? ○ How would you rate how well the care meets your needs, from 0 to 10? ○ What is needed to improve this rating? 	<ul style="list-style-type: none"> ○ What care <i>needs</i> do you have? ○ How do you <i>communicate personal care needs</i>? ○ Do you <i>compare the care</i> that you receive to the care that others receive? ○ Have you received care previously? If yes, <i>how does your experience with this care affect</i> the current home care? ○ Are there any other <i>familiar caregivers</i>? If yes, what do you expect from these caregivers in care provision? ○ How do you know or hear of <i>changes in the care</i> that you receive?
Dealing with caregivers		<ul style="list-style-type: none"> ○ What goes well in how you deal with caregivers? ○ How would you rate how well you deal with care providers, from 0 till 10? ○ What is needed to improve this rating? 	<ul style="list-style-type: none"> ○ Do you have a preference for a <i>more personal or professional care relationship</i> with formal caregivers? ○ Are <i>decisions taken together</i>? ○ Do you <i>feel understood</i> when receiving care? ○ Are caregivers <i>open to your opinions</i>? ○ Do you feel that <i>caregivers think along with you</i>? ○ Is there <i>mutual trust</i> between you and your caregivers? ○ Do caregivers <i>motivate</i> you during care provision? ○ Do you feel <i>treated equally</i>?
Care experiences		<ul style="list-style-type: none"> ○ What is currently going well when receiving care? ○ How would you rate the care that you receive, from 0 to 10? ○ What is needed to improve this rating? 	<ul style="list-style-type: none"> ○ How do you experience <i>the size of the care team</i>? ○ Does the <i>available time</i> influence the care that you receive? ○ How are <i>care appointments followed up</i>? ○ Does the care planning fit into your <i>daily life, such as hobby's, social contacts or work</i>? ○ How do you experience the <i>collaboration</i> when receiving care? ○ How do you experience <i>communication</i> when receiving care? ○ How is the <i>home care that you receive being organised</i> by the [care organisations]? (tools, contact by organisation)
This is what I notice and think about the care		<ul style="list-style-type: none"> ○ Can you cope better with your condition because of the care that you receive from caregivers/How do caregivers support you in your resilience? ○ What are you very satisfied with regarding the care that you receive? ○ Would you recommend your caregivers to others with similar conditions or care needs? How would you rate this on a scale of 0 to 10? ○ Would you recommend [organisations] to others with similar conditions or care needs? How would you rate this on a scale of 0 to 10? ○ What is needed to improve this rating? 	

*Questions were back-to-back translated from Dutch by a native English speaker

plans were seen as most appropriate for reporting, although more insight is needed on how this can be further embedded with existing measures and the care process, in which outcomes are more easily accessible during subsequent evaluations. Moreover, a potential role for other formal caregivers as assessors was mentioned, although some challenges were addressed such as having sufficient communication skills for discussing more emotional topics.

By reflecting on the development process towards an experienced quality measure, some lessons can be drawn. A first application of the developed measure resulted mostly in formulating concrete points of improvement for the primary care process. Although these points of improvement were communicated with the participating direct caregiver, it was unclear if and how the outcomes were also communicated with clients, informal caregivers and other formal caregivers, and if they ultimately resulted in improving the care process for the individual client. This way of working might require a cultural change in the home care setting, focusing not only on person-centred care, but also on relationship-centred care and including multiple stakeholders as more equal partners in the care process.⁴⁹ Insight is therefore needed on how these stakeholders can be involved in clearly discussing discovered improvements and knowing which changes to expect as well as strive towards. This is also related to the requirement stated in the national quality framework, stating the importance for clients to gain insight into quality information in an online accessible care plan, for which technology can be supportive in becoming more self-reliant and striving towards a more equal relationship between clients and formal caregivers.¹⁶ It is therefore important for clients to know what has been discussed during the evaluation (e.g. does the report reflect what I have said or wanted to say) and be aware of specific care agreements made (e.g. what can I expect to change as a result). However, also for informal and formal caregivers (if allowed by the client), it can be important to gain insight into care agreements made to monitor for improvements in specific experienced quality topics or to increase awareness on care provided in a relationship to previously unknown client's preferences, expectations or experiences. Although the responses from participating district nurses regarding the developed optional reporting sheet were diverse, the question remains if existing care plans are suitable in both communicating outcomes and as a reference for comparing outcomes during subsequent evaluations. Moreover, the structured use of reported information on experienced quality can move beyond end-users of the measure and stakeholders in the primary care process since quality management data on the team or organisation level can have value for general quality improvements or as benchmarking for healthcare insurers.

A second lesson was that both informal and formal caregivers found it difficult to respond to questions on experienced quality as perceived by the client. It should be mentioned that telling the experience from a client's perspective can never be expected to be fully known or represented by an (in)formal caregiver. However, the assumption based on the INDEXQUAL framework, was that experiences occur within a relationship of carers all affecting the process of care quality experienced. However, it is maybe better to ask informal and formal caregivers in sharing their own perspective in addition to the perceived client's perspective. This would allow for a more apparent separation between these different perspectives and could support caregivers in both feeling heard and also discussing their needs in the care process. The measure was developed with a more holistic view of health care with an increasing importance of including the client's perspective in measuring experienced quality. Care experiences occur in interactions between individuals in existing care triads, which can consist of clients, informal caregivers, and formal caregivers. As indicated in the founding INDEXQUAL framework, these interactions take place in care relationships that sometimes have stood the test of time, since home care for clients with chronic conditions mostly occur over an extended period.⁴⁸ However, during more acute care situations or for new caregivers, possibly resulting in an initial more task-based approach based on the caregiver's own expertise in similar care situations, it was important to access information on the client's preferences and care experiences help in grasping the experienced quality from a client's perspective.⁵⁰ The results of this study made clear that a balance has to be found in discussing one's own point of view and from a client's perspective, while keeping it manageable to be conducted in around 10 minutes. It is therefore recommended to further refine the measure to leave the perspectives more open or to have different versions of the developed cards specified for each perspective, which can additionally help assessors in applying the measure more easily.

Strengths and limitations

A strength of the current study was the involvement of stakeholders throughout this study by following the principles of PAR. By following a cyclic development approach, participants could be recruited based on the development phase and questions that were at hand. Based on their input, targeted changes could be made throughout the prototyping of the measure as well as providing transparency regarding the rationale behind the steps taken during the process. Although the COVID-19 situation influenced both the methods used and sampling procedure of participants throughout the development process, the methods provided guidance for the development of novel experienced quality measures in the home care setting. However, observations by the research team instead of only audio-recordings could have gained more in-depth

information about the practical application of the measure. Another strength is the participation of different perspectives throughout the development process in which stakeholders were involved representing clients, formal caregivers, and informal caregivers, as well as managers in Dutch home care.

However, this study was also susceptible to some limitations. The applied framework on feasibility and usability requirements imposed a focus on specific components of the developed measure throughout this study, which could have resulted in a lack of attention to other aspects related to embedding the measure in the care process. Although the individual requirements were the result of a stakeholders' needs assessment of existing and desired experienced quality measures, a more focused study is needed into the requirements for implementing the measure in practice. In addition, by primarily relying on recruitment by district nurses during the evaluation in practice, it is likely that this led to a selection bias where clients and triads were included that experienced a more positive care experience or relationship. Also, this study had a limited sample size and focused on a specific client population. Although the results gave some indications that the developed measure and the corresponding visual support using cards are potentially suitable for clients coping with psychological deficits like dementia in sharing their experienced quality. If this is the case, and if the experience quality themes are also relevant to this population are still to be determined in a follow-up study. In this way, it can be made clear if (specific components of) the measure is applicable for a broader range of home care clients in measuring experienced quality. Future studies should also include a more heterogeneous sample of home care clients. In the current study, no vulnerable clients (e.g., low health literacy, cognitive impairments) were included.

Key elements of the method showed to be applicable in other long term care setting. Although the final content and topics addressed during the interviews differ largely between settings, starting points are similar across settings. For example, in nursing home care an assessment method called 'connecting conversations' was developed. Connecting conversation is also a narrative method that assesses experienced quality of care from the client's perspective by conducting separate interviews with formal, informal caregivers and clients.⁵¹ Key elements are that it approaches quality as a dynamic process influenced by expectations and experiences of all involved. Like the method in home care, connecting conversations adopts an appreciative relationship centred approach.

Conclusion

This study indicates that the developed experienced quality measure seems promising regarding the requirements

related to its goal, feasibility in the care setting, and usability in the care process. In a first evaluation study, the measure resulted in most cases in concrete points of improvement for the primary care process of individual clients. However, more insight is needed as to if and how these improvements are communicated, documented, and followed-up in practice. Relating to the development process, the involvement of stakeholders and systematically reflecting on previous defined requirements seems to be of value towards making informed design decisions. By being transparent in terms of the steps taken, care providers as well as organisations can gain insight into the measure's goal, feasibility in home care, and usability for the care process. The principles of the developed measure and preliminary experiences in applying the measure in care practice could aid care providers in seeing the relevance of discussing experienced quality themes for the primary care process and might motivate organisations in allocating resources to apply suitable qualitative measures. To achieve this, an effective implementation strategy has to be developed that fits the measure's goal, targeted population of home care client, and home care setting. In the next step, the measure should be extensively tested and evaluated within a more diverse sample in measuring experienced quality and reflect on its outcomes. In addition, there are indications to explore the suitability of the developed measure for clients with dementia or in need of short-term post-acute home care.

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