
Journal of Participatory Medicine

Advancing the understanding and practice of participatory medicine among health care professionals and patients

Volume 16 (2024) ISSN 2152-7202 Editors-in-Chief: Susan Woods, MD, MPH; Matthew F Hudson, PhD, MPH

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Original Paper

Examining the Feasibility, Acceptability, and Effectiveness of Remote Training on Community-Based Participatory Research: Single-Arm Pre-Post Pilot Study

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Abstract

Background: Over the past decade, a growing body of scientific evidence has demonstrated that community engagement in research leads to more relevant research, enhances the uptake of research findings, and improves clinical outcomes. Despite the increasing need for the integration of community engagement methodologies into the scientific inquiry, doctoral and master's level competencies in the field of psychiatry often lack dedicated training or coursework on community engagement methodologies.

Objective: A total of 13 service users, peer support specialists, caregivers of people with mental health challenges, and scientists (with specialties ranging from basic science to implementation science) aged 18 and older participated in remote training on community-based participatory research. Data were collected at baseline, 2 days, and 3 months.

Methods: A total of 13 service users, peer support specialists, caregivers of people with mental health challenges, and scientists (with specialties ranging from basic science to implementation science) aged 18 and older participated in remote training on community-based participatory research. Data were collected at baseline, 2 days, and 3 months.

Results: The pilot study demonstrated that a 3-month remote training on community-based participatory research ("Partnership Academy") was deemed feasible and acceptable by service users, peer support specialists, caregivers of people with mental health challenges, and scientists. Improvements were found in research engagement and the quality of partnership. A marked increase in distrust in the medical system was also found. Groups submitted 4 grant applications and published 1 peer-reviewed journal at a 3-month follow-up.

Conclusions: This pre- and postpilot study demonstrated it is possible to train groups of service users, peer support specialists, caregivers of people with mental health challenges, and scientists in community-based participatory research. These findings provide preliminary evidence that a 3-month remote training on community-based participatory research ("Partnership Academy") is feasible, acceptable, and potentially associated with improvements in research engagement as well as the quality of partnership and output, such as manuscripts and grant applications.

(*J Particip Med* 2024;16:e48707) doi:[10.2196/48707](https://doi.org/10.2196/48707)

KEYWORDS

community-based participatory research; CBPR; peer support; health literacy; remote training; community-based; user; mental health

Introduction

Over the past decade, growing scientific evidence shows that community engagement in research produces more relevant research, increases uptake of research findings, and improves clinical outcomes [1-6]. Community engagement is defined as “a process of working collaboratively with groups of people who are affiliated by geographic proximity, special interests, or similar situations, with respect to issues affecting their well-being” [1]. Patient-centered outcomes research (PCOR) is intended to improve community engagement in research, yet it often leaves partners feeling overburdened and disenfranchised, leading to premature disengagement from PCOR [6].

Community engagement is crucial to addressing health disparities through the inclusion of historically underrepresented and disadvantaged populations in mental health research. Service users of the mental health system are primarily individuals from low-income groups who have disabilities, multiple chronic health conditions, and low health literacy. This population commonly disengages from research due to mistrust rooted in historical traumatic experiences in the mental health system, which in turn leads to the lack of representation in PCOR. As such, significant investment in the science of community engagement is needed to improve community engagement in PCOR [7].

Despite the need for the integration of community engagement methodologies into the scientific inquiry, doctoral and master’s level competencies in the field of psychiatry commonly do not include dedicated training or coursework on community engagement methodologies [2]. Without appropriate training or research experience, attempts to facilitate community engagement in research are often ineffective and burdensome, leaving partners feeling disengaged [3]. The purpose of this study was to assess the feasibility, acceptability, and preliminary effectiveness of remote training on community-based participatory research—“Partnership Academy.”

Methods

Procedures

The authors participated in and are members of the Early Mortality in People with a Diagnosis of a Serious Mental Illness (SMI) roundtable convened remotely on May 24 and 26, 2022. The roundtable was a diverse, interdisciplinary partnership collaborative composed of individuals with lived experience of mental health or substance misuse, peer support specialists, recovery coaches, parents and caregivers of people with SMIs, researchers and clinician-scientists with and without lived experience, policy makers, and representatives from patient-led organizations committed to addressing the health disparity in early mortality among people with SMIs through patient-centered research. To date, no such collaboration of partners exists. The roundtable aimed to advance the

understanding of fundamental patterns and interactions among and between environmental, behavioral, cultural, neurobiological, psychological, and biopsychosocial mechanisms on health and health behavior relevant to early mortality in people with SMIs.

Roundtable members were selected by reviewing the published literature on early mortality and SMIs. KF and RW conducted a Google Scholar search using variations of the following search terms: “early mortality” and “serious mental illness.” Next, these authors (KF and RW) emailed authors included in the identified prereviewed manuscripts. Identified members recommended additional members through a snowball sampling framework. Patient partners were identified through direct email to partners of the Collaborative Design for Recovery and Health, which is an international group of patients, clinicians, peer support specialists, caregivers, scientists with and without lived experiences, policy makers, and payer systems led by KF and RW. The Collaborative partnered with different community groups from vulnerable populations across the intersectionality of disability and race to coproduce solutions to address community-identified challenges.

Attendants of the Early Mortality in People with a Diagnosis of a Serious Mental Illness roundtable were also given the option to complete surveys before day 1, after day 2, and 3 months after the roundtable. The surveys were used to assess the impact of the training on partners. KF provided participants with a detailed description of the study protocol if they were interested, and a survey link was emailed to individuals with the digital informed consent form. Participants clicked “I agree” on the informed consent form to participate and completed the web-based baseline survey.

The roundtable convening used a remote community meeting method, adhering to the Peer and Academic Partnership model of community engagement [8]. The Peer and Academic Partnership is based on the Center for Disease Control and Prevention’s principles of community engagement (2011) [9], as follows: (1) develop a clear understanding of the purpose, goal, and population involved in community change; (2) become knowledgeable about all aspects of the community; (3) interact and establish relationships with the community; (4) encourage community self-determination; (5) partner with the community; (6) respect community diversity and culture; (7) activate community assets and develop capacity; (8) maintain flexibility; and (9) commit to long-term collaboration. Although the project team initially considered convening in person, the rapid rise in remote meetings due to COVID-19 has highlighted the benefits of remote convening, especially for the early mortality community, given its international representation.

The roundtable members included people across the United States, United Kingdom, Canada, Europe, Africa, Australia, Asia, and the Netherlands. With such a geographically dispersed community, an in-person convening was not feasible for all partners and would have involved disproportionate travel

expenses. To ensure a productive remote meeting, the project team offered to train members to use the virtual platform before the roundtable and planned a rehearsal to work through any last-minute challenges with the meeting platform. Further, to facilitate equitable access to engagement, members were encouraged to call in and not use video if their available technology did not allow for video.

The roundtable convened over two 5-hour days across 1 week in May 2022, structured as a summit with several remote meeting sessions. KF and RW facilitated the summit, set the tone, provided participation guidelines, and kept discussions focused and oriented to the goals of the roundtable. The roundtable used a Delphi method to achieve a consensus on the research agenda. The Delphi method is an empirically supported process used to attain consensus within an expert group [10]. Roundtable members responded to several rounds of PCOR research agenda development. After each round, their responses were aggregated and shared with the group until a consensus was achieved.

Patients made up at least 60% of meeting participants, and all verbal and written materials for the convening meeting were designed with consideration for potential cognitive and intellectual needs, following principles of design for people with SMIs (eg, information presented at fourth-grade level and single structure sentences). Further, all interactions were based on adult learning techniques designed to reduce cognitive effort and promote engagement among all members. For example, KF encouraged the roundtable to share their respective perspectives on early mortality (personal or research-related perspectives) to promote discussions (ie, experiential learning theory), and RW used a round-robin technique to encourage all members to share their ideas, built-in breaks, and energizers into sessions to keep roundtable members engaged, positive, and productive. The community engagement techniques used each day are delineated in the following sections.

Convening Meeting Day 1: Setting the Stage and Story With a Gap

The first session began with a welcome and an opportunity for introductions, followed by a session on the historical literature review of early mortality among people with SMIs. This was followed by a large group discussion intended to identify gaps in our understanding of early mortality among people with SMIs. Next, we presented a Story with a Gap to elicit gaps in the extant research. The Story with a Gap technique includes 2 contrasting pictures of “before” and “after” situations [11]. Following this technique, roundtable members identified the steps and resources needed to move from the “before” to the “after” situation. In conclusion, opportunities to lead committees to work toward tasks identified in the strategic planning process were formed. Next, each member evaluated and ranked their foci for future research, using anonymous polling videoconferencing from the first session to select the 3 highest impact areas within the bounds of financial, time, and other constraints.

Convening Meeting Day 2: Multiple Rounds of Delphi and Consensus

The first session of day 2 began with a draft PCOR research agenda based on discussions from day 1. The PCOR research agenda included, at a minimum, strategies to address gaps in research efforts. All partners commented on the PCOR research agenda and first proposed recommendations publicly in an open forum and, second, proposed additional recommendations anonymously using a Qualtrics web-based survey. This iterative process occurred until a consensus was reached. During day 2 sessions, RW implemented techniques to promote conversation. He used brainstorming, “Go Wild” prompts (ie, asking roundtable members to talk about ideas that begin with “wouldn’t it be good if...”), and reverse brainstorming (ie, considering the reverse of problems) to generate creative, thoughtful, and innovative ideas regarding early mortality PCOR. Then, in the Reality Check session, RW used multivoting, ranking, and problem-solving methods to help the roundtable make decisions about which ideas were most feasible and impactful and how to overcome barriers to their implementation.

Study Design and Participants

The study used a single-arm pre- and postdesign approach to assess the impact of training partners from diverse groups designed to facilitate community-engaged research. Participants (N=13) included service users, peer support specialists, caregivers of people with mental health challenges, and scientists (basic science to implementation scientists).

Ethical Considerations

This study was approved by the Dartmouth Health institutional review board (STUDY02001532).

Instruments

Quality of Partnership

The quality of PCOR was assessed using the Quality of Patient-Centered Outcomes Research Partnerships Instrument (QPCOR) [12]. The QPCOR contains the following domains: (1) purpose, goal, and population; (2) respect (respect community diversity and culture); (3) inclusion (activate community assets); (4) colearning (develop capacity); (5) become knowledgeable about the community; (6) self-determination; (7) shared decision-making (partner with the community); (8) perceived support (interact and establish relationships with the community); (9) flexibility; and (10) sustainability (commitment to long-term collaboration). The QPCOR uses a 10-point Likert scale. Items with a score of 60 or lower indicate the need for improvement and should be addressed. Higher scores indicate higher levels of partnership.

Engagement

Engagement was measured using The Research Engagement Survey Tool (REST). The REST is a 9-item scale that evaluates the level of nonacademic partner engagement among research partners. Example items include “The focus is on problems important to the community” and “All partners assist in establishing roles and related responsibilities for the partnership.”

The REST is measured on 2 Likert-type scales (for quantity and quality). The response options for the quantity scale were “never,” “rarely,” “sometimes,” “often,” “always,” and “not applicable.” The response options for the quality scale were “poor,” “fair,” “good,” “very good,” “excellent,” and “not applicable.” Responses were coded in order from 1 to 5 for both scales, with higher scores indicating higher engagement; not applicable options were coded as missing. For the REST, mean scores were calculated overall for both quality and quantity scales. The overall mean scores for both scales were created by averaging the mean scores so that each response is weighted equally regardless of the number of items.

Distrust in the Medical System

Distrust in the medical system was measured using the Health Care System Distrust Scale [13]. The Health Care System Distrust Scale contains 10 items and is measured on a Likert scale. Example prompts include “Medical experiments can be done on me without my knowing about it” and “My medical records are kept private.” Scores on the Health Care System Distrust Scale range from 12 to 46 with a possible range from 10 to 50. The score is the sum of 10 questions from the Health Care System Distrust Scale after reversing 2 positively framed items. The possible range is from 10 to 50.

Effectiveness

Effectiveness was assessed by collecting data at the 3-month mark, including progress toward grant submissions, submitted manuscripts, and changes in research knowledge.

Data Analysis

Descriptive statistics were conducted to describe the demographic characteristics of the study sample. A paired-sample *t* test was conducted to assess the difference between baseline, day-2, and 3-month scores for statistical significance. Participants served as their own controls from pre- to posttest. Descriptive statistics and analyses were computed using STATA (version 13.1; StataCorp). The statistical models used to analyze the data accommodate missing data, assuming that they are missing at random.

Results

Demographically, the population of this feasibility study was predominantly female ($n=8$, 62%), White ($n=10$, 77%), and

educated at or above a master’s level ($n=8$, 62%). Study participants represented a wide range of adult age groups with the plurality being in the age category of 45-55 years, and there was a wide range of partners represented (Table 1).

For all 3 survey tools used in this study (Healthcare System Distrust Scale, REST, and Quality of Patient-Centered Outcomes Research Measurement tool), there was a marked but not statistically significant increase from pre- to posttest. The Distrust Scale and REST (5-point scales) both increased 0.03 units ($P=.75$ and $P=.85$, respectively), representing increased distrust and research engagement in the postmeeting survey. There was also a marked increase of 6.86 units in the Quality of Patient-Centered Outcomes Research Measurement tool ($P=.20$; Table 2).

When evaluating individual questions, some participants had a more significant degree of change in the postmeeting setting compared to others. In particular, a question regarding providers hiding medical mistakes showed significantly more agreement (mean 3.38, SD 1.04 vs mean 2.69, SD 1.03; $P=.04$; Hedges $g=0.65$), and participants indicated significantly more comfort in engaging with research study team members (mean 91.00, SD 15.36 vs mean 77.15, SD 27.36; $P=.049$; Hedges $g=0.60$) in the postmeeting survey. Many other questions demonstrated meaningful but not significant increases with a universal increase in survey responses for the Quality in Patient-Centered Outcomes Research Measurement tool (ie, change range per question: minimum +3.54; maximum +14.23; Hedges g range: 0.13-0.60).

The Health Care System Distrust Scale included some items that presented an increase on the scale and some that presented a decrease. The most notable increase in distrust was hiding medical errors, as previously mentioned. The most notable decrease (represented by increased trust in the medical system) was related to the health care system putting medical needs as a priority over all other issues during care (mean 2.85, SD 0.99 vs mean 3.31, SD 1.11; $P=.14$; Hedges $g=-0.43$). In the REST tool, there was a minimal change for most questions, with most questions exhibiting a ceiling effect and being near 5 (highest score) in both the pre- and postsetting (Table 3). There were no statistically significant differences in mean scores pre- and postintervention for any domain covered by the REST tool.

Table 1. Sociodemographic characteristics of individuals involved in the research academy. Partner categories are not mutually exclusive, and participants may be represented in multiple categories (N=13).

Characteristics	Values, n (%)
Gender	
Female	8 (62)
Male	5 (39)
Race	
Asian-Eastern	0 (0)
Asian-Indian	0 (0)
Black/African American	2 (15)
Hispanic	0 (0)
Multiple races	1 (8)
Native American	0 (0)
White	10 (77)
Age (years)	
18-24	0 (0)
25-34	1 (8)
35-44	2 (15)
45-54	4 (31)
55-64	3 (23)
65-74	3 (23)
Highest level of education	
Graduate degree or above	8 (62)
Bachelor's degree	2 (15)
High school degree	1 (8)
Other	2 (15)
Partner role	
Caregiver of person(s) with SMI ^a	4 (31)
Service user	4 (31)
Peer support specialist	6 (45)
Scientist	6 (45)
Other	1 (8)

^aSMI: serious mental illness.

Table 2. Pre- and postchanges on outcomes of interest.

Outcome of interest	Prechange, mean (SD)	Postchange, mean (SD)	Mean difference (SD)	P value	Effect size (95% CI) ^a
Health care system distrust	3.08 (0.55)	3.12 (0.50)	0.03 (0.34)	.75	0.06 (−0.69 to 0.80)
REST ^b	4.56 (0.60)	4.60 (0.58)	0.03 (0.60)	.85	0.06 (−0.69 to 0.80)
QPCOR ^c	79.01 (22.80)	85.87 (22.59)	6.86 (18.28)	.20	0.29 (−0.46 to 1.04)

^aHedges g was used to calculate effect sizes (due to the small sample size).

^bREST: Research Engagement Survey Tool.

^cQPCOR: Quality of Patient-Centered Outcomes Research.

Table 3. Pre- and postchanges by individual questions.

Characteristics	Prechange mean (SD)	Postchange mean (SD)	Mean difference SD	P value	Effect size (95% CI) ^a
Healthcare System Distrust Scale^b					
Medical experiments can be done on me without my knowing about it.	2.23 (1.36)	2.23 (1.01)	0 (0)	1.000	0 (−0.74 to 0.74)
My medical records are kept private.	4.23 (0.83)	3.92 (0.76)	−0.31 (0.63)	0.104	−0.37 (−1.12 to 0.38)
People die every day because of mistakes by the health care system.	3.85 (1.07)	3.69 (0.85)	−0.15 (0.90)	0.55	−0.15 (−0.90 to 0.59)
When they take my blood, they do tests they don't tell me about.	2.62 (1.19)	2.31 (0.95)	−0.31 (1.18)	0.37	−0.28 (−1.02 to 0.47)
If a mistake were made in my health care, the health care system would try to hide it from me.	2.69 (1.03)	3.38 (1.04)	0.69 (1.11)	0.040	0.65 (−0.12 to 1.41)
People can get access to my medical records without my approval.	2.54 (0.97)	2.85 (1.07)	0.31 (1.25)	0.393	0.29 (−0.45 to 1.04)
The health care system cares more about holding costs down than it does about doing what is needed for my health.	3.15 (0.99)	3.38 (1.19)	0.23 (1.30)	0.535	0.20 (−0.54 to 0.95)
I receive high-quality medical care from the health care system.	3.62 (1.12)	3.77 (0.97)	0.15 (0.99)	0.585	0.14 (−0.60 to 0.89)
The health care system puts my medical needs above all other considerations when treating my medical problems.	3.31 (1.11)	2.85 (0.99)	−0.46 (1.05)	0.139	−0.43 (−1.18 to 0.33)
Some medicines have things in them that they don't tell you about.	2.62 (1.33)	2.77 (1.17)	0.15 (1.21)	0.656	0.12 (−0.63 to 0.86)
Research Engagement Survey Tool^b					
The focus is on problems important to the community.	4.69 (0.63)	4.76 (0.60)	0.08 (0.95)	0.776	0.12 (−0.87)
All partners assist in establishing roles and related responsibilities for the partnership.	4.53 (0.77)	4.53 (0.88)	0 (1.08)	1.000	0 (−0.74 to 0.74)
Community-engaged activities are continued until the goals (as agreed upon by all partners) are achieved.	4.38 (0.87)	4.38 (0.77)	0 (0.71)	1.000	0 (−0.74 to 0.74)
The partnership adds value to the work of all partners.	4.69 (0.48)	4.61 (0.77)	−0.08 (0.76)	0.721	−0.12 (−0.86 to 0.63)
The team builds on strengths and resources within the community or patient population.	4.62 (0.51)	4.62 (0.65)	0 (0.71)	1.000	0 (−0.74 to 0.74)
All partners' ideas are treated with openness and respect.	4.54 (0.66)	4.69 (0.63)	0.15 (0.80)	0.502	0.23 (−0.52 to 0.98)
All partners agree on the timeline for making shared decisions about the project.	4.46 (0.78)	4.54 (0.78)	0.08 (0.49)	0.585	0.10 (−0.65 to 0.84)
The partnership's processes support trust among all partners.	4.62 (0.65)	4.69 (0.63)	0.07 (0.95)	0.776	0.12 (−0.63 to 0.86)
Mutual respect exists among all partners.	4.54 (0.66)	4.54 (0.88)	0 (1.00)	1.000	0 (−0.74 to 0.74)
Quality of Patient-Centered Outcomes Research^c					
I had a clear understanding of the purpose of the study.	78.6 (26.27)	82.92 (26.44)	4.31 (15.00)	0.321	0.16 (−0.59 to 0.90)
I felt listened to.	76.54 (26.98)	85.62 (28.81)	9.08 (26.90)	0.247	0.31 (−0.44 to 1.06)

Characteristics	Prechange mean (SD)	Postchange mean (SD)	Mean difference SD	P value	Effect size (95% CI) ^a
I felt prepared to be an equal partner in the research study.	80.77 (24.17)	84.62 (21.43)	3.85 (16.26)	0.411	0.16 (−0.58 to 0.91)
Researchers were knowledgeable about people like me or were willing to learn about people like me.	81.77 (21.60)	86.69 (20.38)	4.92 (24.28)	0.479	0.23 (−0.52 to 0.97)
I believe that I had choices in how I could be part of the research study.	80.38 (24.10)	83.93 (28.50)	3.54 (28.98)	0.668	0.13 (−0.62 to 0.87)
I feel prepared to be an equal partner in the research study.	80.92 (25.28)	84.62 (26.26)	3.69 (21.65)	0.550	0.14 (−0.60 to 0.88)
I feel accepted by all members of the research study team.	80.31 (24.30)	85.85 (26.87)	5.54 (24.65)	0.434	0.21 (−0.54 to 0.95)
Researchers used language that was consistent with my values and culture.	77.69 (27.64)	84.77 (26.31)	7.08 (24.52)	0.319	0.25 (−0.50 to 1.00)
Both community members and researchers are thinking of ways we can continue to work together in the future.	75.00 (27.49)	89.23 (18.58)	14.23 (29.62)	0.109	0.59 (−0.18 to 1.34)
I felt comfortable engaging with the members of the research study team.	77.15 (27.36)	91.00 (15.36)	13.85 (22.85)	0.049	0.60 (−0.17 to 1.36)
I felt my views were incorporated into the research study.	79.92 (27.89)	85.31 (26.07)	5.38 (18.71)	0.320	0.19 (−0.56 to 0.94)

^aHedges *g* was used to calculate effect size (due to the small sample size).

^bOn a 5-point Likert scale.

^cOn a 10-point scale.

Discussion

Principal Findings

The purpose of this study was to assess the feasibility, acceptability, and preliminary effectiveness of remote training on community-based participatory research. The Partnership Academy was found to be feasible and acceptable. Improvements were found in research engagement and the quality of the partnership. A marked increase in distrust in the medical system was also found. Three months after the Partnership Academy training, the trainees submitted 4 grant applications and published 1 peer reviewed research article.

Feasibility and acceptability by service users, peer support specialists, caregivers of people with mental health challenges, and scientists were demonstrated through their capacity to attend and participate in the Partnership Academy. With the geographically dispersed community of the Partnership Academy, an in-person meeting might not be feasible for all partners and could invoke disproportionate travel expenses. Remote training allowed partners from all parts of the United States to meet and work together while avoiding travel, accommodation, and facility rental expenses. Further, all aspects of the remote training were aligned with the Americans with Disability Act requirements. For example, patients with cognitive impairments may have difficulty using Zoom due to challenges related to motion sensitivity. As such, there was no requirement to use the video feature.

The Partnership Academy was found to be potentially effective in promoting research engagement. Greater alignment of partner

priorities and researchers' objectives facilitates greater engagement in all parts of the research process, from study conceptualization to knowledge mobilization, ultimately increasing the likelihood of an intervention's success [14]. This shift goes beyond a paradigm where research functions as a one-way conversation, to one in which active community participation has facilitated and enabled greater integration and engagement of partners and researchers alike [15]. The model of the Partnership Academy exemplifies these concepts and practically implements their use, providing evidence for the potential effectiveness of this approach in prospective research projects. Other trainings are available, such as the Community-based Participatory Research Academy [16] and Patient-Centered Outcomes Research Institute's Research Fundamentals: Preparing You to Successfully Contribute to Research; however, they have not been designed for the unique needs of people with SMIs.

A marked increase in distrust in the medical system was also found. There are a few possible explanations for an increase in distrust in a medical system, in particular concerns for medical errors. First, it is possible that increased awareness from the conversations during the training led to further entrenchment in previously held beliefs. Second, it is possible that during the 2-day training, the roundtable participants heard not only more negative stories about the medical errors but also negative stories from fellow roundtable members who were deemed "credible" as scientists, expressing their concern with medical errors. Integrating qualitative data collection in future roundtable events may elicit new knowledge regarding perceptions of mistrust among participants.

Limitations

Due to the nature of the study and the study design, there are inherent limitations. There are additional limitations surrounding the study design and analysis of data. Due to the small sample size, we could not stratify participants by demographic characteristics or differing experiences with different SMIs. It is unknown if different participants with different diagnoses, or researchers who engaged in diagnosis-specific research had different program evaluations. Additionally, due to the Likert-scale measurements, understanding the true magnitude of the effect is limited to categorical shifts and not continuous measurement changes. Moreover, Likert questions open the study up to potential acquiescence bias due to participants' potential to overly agree with statements (in comparison to their actual feelings). Due to the sampling methodology used, those selected for participation in the roundtable were those who were actively engaged in the health care system or research, and these findings may not apply to the population with SMI. Lastly, less than 25% of the study population represents racial minorities or those with lower levels of education. Future studies should make an effort to recruit a more diverse group of participants.

Conclusions

This pre- and postpilot study demonstrated the possibility of training groups of service users, peer support specialists, caregivers of people with mental health challenges, and scientists

in community-based participatory research. These findings provide preliminary evidence that a 3-month remote training on community-based participatory research ("Partnership Academy") is feasible and acceptable and potentially associated with improvements in research engagement as well as the quality of partnership and output, including coproduced grant applications and peer-reviewed manuscripts.

Addressing the multifaceted health needs as well as the mental and behavioral health needs of diverse individuals, families, and communities in the United States is a complex issue that warrants attention from clinicians, researchers, scientists, public health professionals, and policy makers. The use of a community-based participatory framework supports the notion of implementing innovative approaches to help address health and mental health disparities. Moreover, our study reinforces key tenets of values delineated through inventive collaborations and partnerships that may be promising. In particular, our engagement and training efforts suggest the significance of (1) building trust and relationships, (2) establishing a shared purpose and vision for the achievement of goals, (3) engendering transparency and effective communication, and (4) performing continuous quality improvement or process and outcome evaluation where appropriate. Advancing health equity requires multidimensional, multisectoral, and interdisciplinary approaches to adequately address the needs of ethically and culturally diverse populations.

Conflicts of Interest

KF receives funding from Social Wellness and partners with Emissary Health, Inc. The other authors declare no conflicts of interest.

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Abbreviations

PCOR: patient-centered outcomes research

QPCOR: Quality of Patient-Centered Outcomes Research Partnerships Instrument

REST: Research Engagement Survey Tool

SMI: serious mental illness

Edited by M Hudson; submitted 03.05.23; peer-reviewed by H Traino, A Higaki, V Girishan Prabhu; comments to author 16.06.23; revised version received 22.09.23; accepted 19.11.23; published 01.03.24.

Please cite as:

Fortuna K, Bohm A, Lebby S, Holden K, Agic B, Cosco TD, Walker R

Examining the Feasibility, Acceptability, and Effectiveness of Remote Training on Community-Based Participatory Research: Single-Arm Pre-Post Pilot Study

J Particip Med 2024;16:e48707

URL: <https://jopm.jmir.org/2024/1/e48707>

doi: [10.2196/48707](https://doi.org/10.2196/48707)

PMID: [38427414](https://pubmed.ncbi.nlm.nih.gov/38427414/)

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Original Paper

Tracking the Development of Community Engagement Over Time: Realist Qualitative Study

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Abstract

Background: A growing interest in engaging communities in the development of health care services and communities has not automatically led to progress or consensus as to how to engage communities successfully, despite the evidence base showing how to leverage enablers and alleviate barriers.

Objective: To bridge the gap between the evidence base and which community engagement (CE) approaches have actually been applied in practice over time, this study aims to investigate how CE approaches have changed over the past 4 years in 6 different regions in the Netherlands and citizens' and professionals' experiences underlying these changes.

Methods: For the last stage of a multiple case study following the development of CE approaches in 6 different regions in the Netherlands, a realist qualitative case study was conducted. To investigate how CE approaches had changed over the past 4 years, data from the entire 4 years of the study were used, including documents, interview transcripts, and observations. To examine citizens' and professionals' experiences underlying these changes, new interviews were conducted. The latest interview results were discussed with a panel to ensure the results had face validity.

Results: The regions had implemented different types of CE approaches over the past 4 years and were adapting these approaches over time. Many of the (remaining) approaches may be operating on a smaller scale. The study identified the following overarching themes along which CE had been adapted: fewer region-wide approaches and more community-focused approaches, more focus on building relationships with (already engaged) citizens and community-led initiatives, and more focus on practical and tangible health promotion and social cohesion activities and less focus on complex "abstract" programs. The study identified a further 4 overarching themes highlighting citizens' and professionals' experiences underlying these changes in the CE approaches: a lack of engagement environment, need for facilitative leadership from organizations, need for a clear and shared vision underscoring the importance of CE, and misalignment between citizens' and professionals' perspectives and motivations for CE. All participants had experienced the engagement environment as insufficient. To support CE, professionals experienced the need to develop and receive more facilitative leadership and to develop approaches better equipped to involve citizens in the decision-making process. Citizens experienced the need to better align citizens' and professionals' motivations and aims for CE approaches and to receive longer-term financial support for their community-led initiatives.

Conclusions: This study suggests that CE has not yet been embedded within organizational cultures. This has arguably meant that the (remaining) CE approaches are operating on a smaller scale. To enable the further development of CE approaches, an investment in the engagement environment and a shared vision is required. Only then could CE within the regions move beyond the more seemingly smaller-scale CE approaches.

(*J Particip Med* 2024;16:e47500) doi:[10.2196/47500](https://doi.org/10.2196/47500)

KEYWORDS

community engagement; citizen involvement; health care; decentralization; realist evaluation

Introduction

Background

Over the past few decades, public sector organizations have increasingly been trying to engage citizens in shaping and improving health care services, neighborhoods, and healthy living environments [1,2]. The idea behind community engagement (CE) is that through citizens' involvement services and policies will better reflect communities' experiences and better address their needs [3-7]. The aim of CE approaches is to involve citizens in the decision-making, planning, designing, governance, or delivery of services and policies. CE approaches can range from consultation where citizens have limited power to influence decision-making to partnership and (shared) leadership, where citizens have decision-making control [1,8,9]. The approaches can take many different forms, including citizen advisory panels, citizen budgetary forums, peer service delivery, and community-led initiatives [1].

However, as Beresford [10] noted, this increasing and widespread interest in involving communities in the development and improvement of health care services and living environments does not automatically mean progress or consensus as to how to do so meaningfully and successfully for either organizations or communities. Previous literature hints at the barriers that have hindered this progress toward CE over the past few years. For example, Cook and Kothari [11] argued that many participatory processes are often undertaken uncritically based on the perceived wisdom of the overwhelming benefits of CE. However, these formulaic approaches often impose the views, objectives, and aims of organizations onto communities, resulting in benefits that primarily serve the organizations themselves, or, more commonly, fail to deliver benefits to either organizations or communities. Previous literature has described other important factors driving this lack of progress, such as power imbalances between organizations and communities, engaged citizens' limited credibility according to professionals, communities' lack of influence in decision-making processes, misaligned interests between organizations and between organizations and communities, or a lack of a clear and shared vision for CE [5,10,12-14].

Despite the wealth of previous literature identifying important barriers and enablers to the progress of CE, health and care organizations are still searching for how to implement their own successful CE approaches and largely have not yet taken the required steps to leverage these identified enablers [14] or improved the engagement environment sufficiently [14]. Moreover, previous literature has not investigated how CE has

developed over time. Because of this gap between the evidence base and how the implementation process of CE approaches over time is actually experienced in practice, this study examined how CE developed during the course of 4 years in practice. To provide insight into the development of CE in the Netherlands, we conducted a 4-year multiple case study investigating how 6 different regions are developing and implementing their own CE approaches. The initial phase of the study involved conducting an international rapid realist review to identify the barriers and enablers for engaging communities. This review resulted in the development of 8 guiding principles for the successful implementation of CE [13]. Subsequently, these principles were tested in practice through various case studies, leading to the identification of a ninth guiding principle [13-16].

Objective

Building on the previous stages by using the guiding principles as program theories, this paper describes the final stage of the study. This final case study aims to investigate how CE has changed over the past 4 years in the 6 regions and to examine citizens' and professionals' experiences underlying these changes. This paper explored the following research questions:

1. What CE approaches have been applied, and how have these approaches changed over the past 4 years?
2. What are citizens' and professionals' experiences underlying the changes in CE approaches? What are the contextual factors and mechanisms explaining these experiences?

Methods

Overview

This paper presents the last stage of this multiple case study (T4). This final stage examined how CE approaches have changed over the past 4 years and what citizens' and professionals' experiences were underlying these changes. The study was informed by the realist evaluation (RE) approach. The RE approach seeks to explain the causal relationship between contexts, mechanisms, and outcomes in particular programs of interest [17]. In this way, the study sought to understand the causation behind the changes in CE approaches and to understand which (enabling and constraining) mechanisms were triggered within the (changing) contexts of the 6 regions and how these influenced citizens' and professionals' experiences of developing CE (Textbox 1 [13], [14], [18]; Multimedia Appendix 1).

Textbox 1. Community engagement-oriented definitions of realist concepts [13,14,18].

Intervention

This refers to interventions' implemented activities, strategies, and resources [19], for example, citizen advisory panel meetings or neighborhood organized workshops.

Context

This pertains to the backdrop of an intervention and includes the preexisting organizational structures, cultural norm of the community, the nature and scope of preexisting networks, and geographic location effects [20-22].

Mechanism

This refers to what "triggers" participants to want to participate or not in an intervention. "Mechanism" does not refer to the intentional resources offered or strategies implemented within an intervention. Mechanisms usually relate to cognitive, emotional, and behavioral responses to intervention resources or strategies [20]. Mechanisms are usually hidden, sensitive to variations in context, and generate outcomes [23], for example, citizens feeling more empowered because of learning opportunities.

Outcome

Refers to intended, unintended, or expected intervention outcomes [20], for example, sustainability, quality, and integration of services (macro); citizens' level of involvement in health and care services (eg, in designing policies; meso); and citizens' health and well-being outcomes (micro).

Context-mechanism-outcome (CMO)

To understand how certain contextual factors shape or trigger the mechanism, causal links are expressed through "context-mechanism-outcome configurations." Formulating and refining CMOs is largely how researchers analyze data in realist evaluation as it allows a deeper understanding of which (aspects of) interventions work, for whom, under which circumstances, and to what extent [24]. CMOs are also used to generate or refine program theories, which in turn help shape the final product of an evaluation (eg, recommendations). CMOs are also used to generate or refine program theories.

For this 4-year multiple case study, 6 different regions within the Netherlands were chosen as the research sites ([Multimedia Appendix 2](#)). The different contextual factors and the different CE approaches within the regions helped to compare and contrast citizens' and professionals' experiences accordingly. For the first research question regarding what CE approaches have been applied and how the approaches have changed over the past 4 years, data from the entire 4-year multiple case study were used. Data sources to answer the first research question included (strategy) documents, completed observation templates (based on stakeholders' meetings, workshops, and activities), transcripts of (group) interviews with stakeholders, and reference panel workshop discussions [13-16]. For the second research question, which focuses on understanding the experiences of both citizens and professionals that underlie changes in CE approaches, only the most recent round of data collection (T4) was used. Data sources for this last data collection round included (new strategy) documents, (new) interviews with stakeholders, and the last reference panel workshop (T4).

Recruitment and Study Sample

The last data collection round was first based on interviews with professionals (n=7; this included policy makers, project managers, local councilors, and health care professionals) and

with citizens involved in organizationally led projects and community-led initiatives (3) in the 6 different regions in the Netherlands (T4; [Table 1](#); [Multimedia Appendix 2](#)). For this study, purposive sampling [25] was used to ensure different professionals and citizens from each of the 6 regions were included in the sample. As much as possible, the same citizen and professional participants as in the previous stages of the 4-year multiple case study were approached and interviewed, thus hoping to enable a better view of how participants' experiences had developed over the years. Professionals and citizens were recruited through the reference panel members' networks. Almost all approached participants agreed to take part in video or telephone interviews and had signed consent forms, except for participants in region B who only agreed to take part in the reference panel. Ultimately, a total of 10 interviews (1 dyad with a local councilor and a project manager), each lasting approximately 1.5 hours were conducted. Unfortunately owing to the COVID-19 pandemic, researchers were prevented from meeting participants face-to-face and interviews could only be conducted remotely through video or telephone calls. Interviews were conducted until the authors agreed the point of data saturation was reached or when no new themes emerged and when there was a high rate of recurrence of responses [26].

Table 1. Description of the regions and sample size [14].

Region	Region description	Sample size at this stage of the study (T4)
A	<ul style="list-style-type: none"> Rural region made up of several smaller municipalities, struggling with aging population and economic decline (number of residents=106,500) Expected average age at birth and expected average age in good health were 80.9-81.6 years and 47.9 years Socioeconomic status variable according to different neighborhoods with pockets of deprivation and more affluent areas Quality of life in neighborhoods varied accordingly. Region with declining and aging population 	<ul style="list-style-type: none"> 1 interview with policy maker 1 interview with engaged citizen 1 (different) policy maker involved in the reference panel
B	<ul style="list-style-type: none"> Region with a mix of rural and urban areas, with significant health disparities (number of residents=270,000) Expected age at birth and expected average age in good health 78.2 to 79.6 years and 45.2 years Socioeconomic status variable according to different neighborhoods but included more deprived neighborhoods due to the traditional industry in the area having been closed down Quality of life varied accordingly 	<ul style="list-style-type: none"> 2 patient and public involvement professionals engaged in reference panel (not interview)
C	<ul style="list-style-type: none"> Rural municipality with 13 different villages with favorable unemployment and welfare support rates compared to the national average (number of residents=27,500). Expected average age at birth and expected age in good health 82.0 to 48.7 years Socioeconomic status higher than the national average Quality of life higher than the national average 	<ul style="list-style-type: none"> 2 interviews with 2 policy makers
D	<ul style="list-style-type: none"> Region with a mix of rural and urban areas, with significant health disparities and less favorable unemployment and welfare support rates compared to the national average (number of residents=27.500) Expected average age at birth and expected average age in good health 80.5 to 84.7 years and 45.2 to 47.1 years Socioeconomic status variable according to different neighborhoods but includes more deprived neighborhoods due to the traditional industry in the area having been closed down Quality of life varied accordingly but has an aging population 	<ul style="list-style-type: none"> 1 interview with a professional 2 citizens engaged in the reference panel
E	<ul style="list-style-type: none"> Rural region made up of 4 municipalities with pockets of health disparities (number of residents=120,000). Expected average age at birth and expected average age in good health 80.4 to 82.0 years and 48.2 years Socioeconomic status higher than the national average but with pockets of significant deprivation (differences between the statuses) Quality of life on average higher than the national average 	<ul style="list-style-type: none"> 1 dyad interview with 1 policy maker and 1 project manager
F	<ul style="list-style-type: none"> Suburban municipality with favorable unemployment and welfare support rates compared to the national average (number of residents=41,000) Expected average age at birth and expected average age in good health 81.3 years and 45.5 years Socioeconomic status in line with national average Quality of life in line with national average 	<ul style="list-style-type: none"> 1 interview with a public health professional 1 interview with an engaged citizen 1 interview with an engaged citizen Same citizens engaged in the reference panel

Reference Panel

The 4-year multiple case study was conducted in collaboration with a reference panel. The panel consisted of stakeholders involved in developing CE approaches within the 6 different regions, including policy makers; involved citizens; members of patient and public involvement organizations; and experts in the field of public health, health inequalities, and citizen participation. The panel, therefore, helped to ensure that the study addressed stakeholders' questions regarding CE and addressed relevant gaps in the literature. For this data collection round (T4), the panel also helped with the sample selection and

recruitment process. Furthermore, the interview findings were discussed with the reference panel to further enrich the results and to ensure that the results had face validity. [Multimedia Appendix 2](#) highlights the participants (n=17) present during the workshop to whom the interview findings of this last study were presented.

For the final study (T4), participants were asked to draw up their own storyboards to reflect on the development of their own CE approaches during web-based or telephone interviews. Owing to the COVID-19 pandemic and to reduce the burden on participants, participants were given the option of drawing or writing on the web-based storyboard themselves or instructing

the researchers how to do it for them. The storyboards aimed to enable participants to reflect in a more participative and creative way on their experiences and perceptions regarding the development of CE more broadly. The storyboards highlighted not only the broader experiences but also specifically the enablers and barriers and the support needs going forward [27-29]. Participants were asked to consider the following three questions when drawing up their storyboards: (1) which successful steps they had taken with the development of CE and which enablers they had experienced, (2) which negative results they perceived during the development of CE and barriers they experienced, (3) how these enablers and barriers have changed their CE approaches going forward.

During the second part of the interview, participants were asked to consider their storyboard and imagine they had to advise someone else to successfully develop a CE project. They were asked to note their advice down on notecards. After this, participants were asked to cluster their advice into two groups: (1) what advice they already follow themselves and (2) what advice they struggle to implement themselves. By clustering current enablers and barriers in this way, and discussing the underlying reasons, the study aimed to highlight practical advice to enable stakeholders to implement their new CE approaches [27,28,30]. The interview data were collected between February and May 2020.

After the initial analysis of the interviews and the secondary data, the anonymized results were shared and discussed during a workshop with the reference panel (Multimedia Appendix 2). This further refined and enriched the results. The workshop was held in January 2021.

Finally, to supplement and triangulate the interview data, the authors conducted a document analysis from the field notes taken over the 4 years of study and from the regions' strategy documents.

Data Analysis

To help answer the first research question (regarding the changes in CE approaches), the authors re-examined previous interview transcripts, observation templates, and documents. The authors also classified the CE approaches at “the consultation level”—whereby citizens provide information to organizations, “the communication level”—whereby citizens receive information from organizations, or “the participation level”—whereby citizens are actively engaged in dialogue with organizations and are actively involved in the planning, implementation, or decision-making—of approaches as in line with the findings of the previous studies [14]. To answer the second research question (regarding citizens' and professionals' underlying experiences), the same researchers who had been involved during the entire 4 years of this study applied an inductive and deductive analysis approach to the last round of interviews (T4). Inductively, we searched for (1) changes in CE approaches; (2) citizens' and professionals' experiences in developing and implementing CE, including enablers and barriers; and (3) required support to further develop CE. After this open coding and analysis, the researchers also deductively applied the guiding principles within the coding structure and analysis approach. These guiding principles are as follows: (1)

ensure staff provide supportive and facilitative leadership to citizens; (2) foster a safe and trusting environment enabling citizens to provide input; (3) ensure citizens' early involvement; (4) share decision-making and governance control with citizens; (5) acknowledge and address citizens' experiences of power imbalances between citizens and professionals; (6) invest in citizens who feel they lack the skills and confidence to engage; (7) create quick and tangible wins; (8) consider both citizens' and organizations' motivations; and (9) develop a shared vision with clear roles for professionals and citizens, ensuring communities' diversity is reflected within the vision [13,14].

To examine how CE has been developed and changed over the past 4 years and what citizens' and professionals' experiences were underlying these changes in 6 different regions in the Netherlands, the authors constructed context-mechanism-outcome (CMO) configurations within each interview transcript to examine the contextual factors and mechanisms underlying these changes and to investigate participants' experiences. Interviews were thus coded and analyzed using CMOs, which were drafted and analyzed in MAXQDA (VERBI GmbH) by EdW, and discussed by all authors. To aid authors during the data analysis process and to ensure consistency and transparency, the authors applied the same CE-oriented definitions of “interventions,” “contexts,” “mechanisms,” and “outcomes” (Textbox 1). The clustering followed a sequential and iterative process that has been applied in previous studies and described elsewhere [13,14]. CMOs were coded and clustered into (1) changes in CE approaches over the past 4 years, (2) participants' experiences (including enablers and barriers), and (3) required support to further develop and implement CE. The authors discussed the clusters and thematically analyzed, reviewed, and discussed them again. The final draft of the clustered CMOs was shared with all authors to confirm and refine the themes (Multimedia Appendix 3). Afterward, for the deductive analysis, the transcripts and the CMOs were coded and clustered according to the 9 guiding principles.

Ethical Considerations

The study received ethics approval from Tilburg University (reference EC-2017.96). All participants were provided with information letters concerning the study and had time to ask any questions they may have had. It was also made clear that participation was completely voluntary. Afterward, all participants signed forms stating their consent to participate. This is in accordance with Dutch national guidelines.

Results

Overview

The following section will first describe how CE approaches have changed over the past 4 years (Table 2). The study indicates that there are 3 overarching themes regarding the changes in CE approaches. Theme 1: moving away from region-wide approaches to more community-focused approaches. Theme 2: more focus on building relationships with (already-engaged) citizens and community-led initiatives. Theme 3: more focus on practical and tangible health promotion and

social cohesion activities instead of on more complex “abstract” programs

Table 2. Cross-sectional summary of community engagement approaches over the past 4 years [14].

Region	Interview round 1: 2016-2017	Interview round 2: 2018-2019	Final interview round: 2020-2021
Region A	<ul style="list-style-type: none"> • Communication level <ul style="list-style-type: none"> • Regional web-based community platform highlighting the projects and meetings being organized by the regional health care board. • As part of the web-based community, hoped to develop “an instrument” to increase the region’s self-management capacity (not developed). • Consultation level <ul style="list-style-type: none"> • Regional web-based community platform to create propositions and test these among citizens and health and care organizations. In this way, the regional health and care board hoped to learn key issues facing health and care organizations and the residents (eg, experiences, needs, projects, or meetings). • Participation level <ul style="list-style-type: none"> • Regional web-based community platform, supported by occasional physical meetings, to enable dialogue between residents, municipalities, health care professionals, clients, schools, and volunteer clubs (eg, sports clubs), businesses, and health and care organizations about how health and care services can become futureproof and maintain its quality and efficiency. Online community aimed at increasing social between engaged or interested residents, organizations, and other stakeholders of the regional health and care system. 	<ul style="list-style-type: none"> • Consultation level <ul style="list-style-type: none"> • Regional public health organization, commissioned on behalf of one of the region’s municipalities, conducted interviews and focus groups with residents to discuss their perceptions and experiences of what it is like to live in that municipality (completed). • Public health organization region A held informal dinner events with older residents to discuss their current and future health and care needs and the sort of local amenities they would like to have available in the municipality (completed). • Regional living room: supports organizations and residents to address urgent health and care issues in the region. “Living rooms” across the province have been set up for residents to investigate such issues together (ongoing but by different organization). • Participation level <ul style="list-style-type: none"> • Regional web-based community: online platform, which enabled all residents and professionals within the region to share and collect information regarding the region’s health care system. The platform also enabled residents to share their ideas of how future health and care services should take shape in the region (disbanded). 	<ul style="list-style-type: none"> • Participation level <ul style="list-style-type: none"> • Municipality within the region had started a project to improve the living environment of 1 village with the aim of also contributing to the green energy transition in the municipality. The municipality together with the village council had set up the project (completed). • Municipality searching for ways to include citizens (especially older citizens) in the reconfiguration of health and care services within 1 municipality. To date, it had not found a way to involve citizens on the “participation level” (ongoing).

Region	Interview round 1: 2016-2017	Interview round 2: 2018-2019	Final interview round: 2020-2021
Region B	<ul style="list-style-type: none"> • Communication level <ul style="list-style-type: none"> • Developed guidelines or how-to guide to stimulate the engagement of the >65 years age group for specific neighborhood projects and development. Guideline was developed through interviews with residents aged >65 years in the region about their engagement experiences (completed). • Participation level <ul style="list-style-type: none"> • Looking for ways to leverage all the separate existing citizen representative bodies (eg, village councils, client councils, and church councils) that can be leveraged to increase citizen representation on the regional governance level. Currently, these approaches all operate separately from each other and on a more local level. • A retired surgeon and a representative of a regional PPIa organization were members of the regional health care governance board (surgeon no longer involved). 	<ul style="list-style-type: none"> • Communication level <ul style="list-style-type: none"> • PPI^a organization freely distributed a magazine to all residents in the region and promoted healthy living and community engagement activities and projects (ongoing). • Participation level <ul style="list-style-type: none"> • “WeHelpen” web-based platform that enables residents to ask for and provide each other with informal help, from mowing each other’s grass to social visits and doing groceries for the less abled (ongoing). • A local resident and a representative of a regional PPI organization were members of the regional health care governance board (resident no longer taking part, PPI representative still present). 	<ul style="list-style-type: none"> • Communication level <ul style="list-style-type: none"> • PPI organization “educated” citizens on self-management and the concept of positive health, for example, workshops and conferences (ongoing). • Participation level <ul style="list-style-type: none"> • PPI organization advised health and care organizations on how to involve patients and citizens in their projects (ongoing). • PPI organization provided training to patients on how to be involved (ongoing).
Region C	<ul style="list-style-type: none"> • Communication level <ul style="list-style-type: none"> • Using visualizations of broader health and care concept “positive health” to discuss and develop municipal-wide policies and projects with residents and using the visualization as a financial lever for change (only projects highlighting they contribute to the positive health of residents; ongoing). • Looking to develop jargon-free language to engage residents (ongoing). • Participation level <ul style="list-style-type: none"> • Looking for ways to engage children, young adults, and parents to help develop municipality’s youth care policies (ongoing). 	<ul style="list-style-type: none"> • Participation level <ul style="list-style-type: none"> • Municipality professionals working to establish closer working relationships with residents, local sports clubs, and village council (ongoing). • Municipality was working to establish closer relationships with schools, parents, and students to engage them in the development and improvement of the municipality’s youth policy (ongoing). • Involved citizens in the development of integrated local health policy (completed). 	<ul style="list-style-type: none"> • Consultation level <ul style="list-style-type: none"> • Used interviews to gain insight into low-income residents’ experiences and needs regarding low-income support and thus to align low-income policies more to low-income residents’ needs (completed).
Region D			

Region	Interview round 1: 2016-2017	Interview round 2: 2018-2019	Final interview round: 2020-2021
	<ul style="list-style-type: none"> • Communication level <ul style="list-style-type: none"> • Looking for “tools” to increase citizens’ awareness regarding positive health and to engage citizens in projects regarding positive health (completed). • Took part in health care markets to raise awareness for healthy living lifestyles (completed). • Participation level <ul style="list-style-type: none"> • Started their own nonmandatory client council with the idea that clients within the region can be involved in creating new projects and to share which aspects are important to their own positive health (disbanded). • Considering developing their own “Digipanel” to enable citizens to share their thoughts on policy developments (not developed). 	<ul style="list-style-type: none"> • Consultation level <ul style="list-style-type: none"> • Conducted patient satisfaction surveys for general practices as part of a new quality improvement system whereby practices will be monitored as to whether they are implementing measures to improve areas highlighted in the survey (in an attempt to make general practices more accountable to the patients; completed and considering running again). • Community-led initiative kicked-off with passing around a “village diary.” The volunteers went door-to-door with the diary to ask their neighbors to write something about their village, for example, what they liked about the village and what local amenities they felt were missing. Volunteers then used the diary as the foundation for the community-led initiative (completed). • Communication level <ul style="list-style-type: none"> • Workshops for residents with the aim of promoting “positive health” (ongoing). • With the aim of setting up better working relationships between a local municipality and the community-led initiatives, a PPI and citizen representative organization held separate workshops with the municipality and with the initiatives to gain insight into how to improve their collaboration. At the end of the learning program, the organization was hoping to have 1 joined workshop (completed). • Participation level <ul style="list-style-type: none"> • Primary care group’s client council (disbanded). • A community-led village initiative was set up when the village’s only general practitioner retired. The community-led initiative, had at the time of interviewing, set up a multidisciplinary medical center, a free library and reading nook, a shared neighborhood-allotment, social activities and evenings, and were working to expand the center’s remit. • Resident village support worker who maintained close links within their own communities and ensured that the health, care, and living needs of their neighbors were being addressed (whenever possible by village residents themselves and otherwise, the village support worker ensured appropriate support from the municipality was made available; ongoing). 	<ul style="list-style-type: none"> • Participation level <ul style="list-style-type: none"> • Community-led initiative continued to grow and looked to keep promoting social cohesion and social activities. They especially looked to keep this going during the COVID-19 crisis. Also looking to take on a commissioning role for certain health and care services. • Resident village support worker continued his linking pin role, especially during the COVID-19 crisis.

Region	Interview round 1: 2016-2017	Interview round 2: 2018-2019	Final interview round: 2020-2021
Region E	<ul style="list-style-type: none"> • Communication level <ul style="list-style-type: none"> • Several municipalities had conducted a “health scan” with residents to investigate and discuss what key issues they were facing (completed). • Participation level <ul style="list-style-type: none"> • The biggest insurance companies, local municipalities, and health and care providers had set up a Policyholder Cooperation to ensure policyholders could have a say in which services should be included within the insurance package and could help shape the local health care system. They wanted to provide all policyholders to be able to vote on important decisions and were looking to recruit policyholders to be on the board. • Residents within some of the villages had created some groups to raise awareness for healthy living lifestyles (eg, through walking groups, setting up social meetings, and running events). Municipality is looking for ways to support these groups (ongoing). 	<ul style="list-style-type: none"> • Communication level <ul style="list-style-type: none"> • Annual policyholder events and workshops promoting positive health (disbanded) • Local municipalities were establishing closer relationships with community-led initiatives and sports clubs with the aim of improving children’s and young people’s health (ongoing) • A “Self-care for me” website, which enabled local residents to score their own health. The local municipalities were hoping to get local businesses involved to set up “fun challenges” improving residents’ health (ongoing). • Participation level <ul style="list-style-type: none"> • The biggest insurance companies, local municipalities, and health and care providers had set up a Policyholder Cooperation to ensure policyholders could have a say in which services should be included within the insurance package and could help shape the local health care system (disbanded). 	<ul style="list-style-type: none"> • Communication level <ul style="list-style-type: none"> • Looking to implement 1 contact person at municipalities for community-led initiatives.
Region F	<ul style="list-style-type: none"> • Participation level <ul style="list-style-type: none"> • Project initiated by regional public health organization to support low-income families. Parents from these families are involved in the projects highlighting important priorities and activities. Parents are also involved in the implementation of activities (completed). • Community-led initiative set up to promote the positive health in the community by organizing health promotion activities (eg, benches along walking paths; ongoing). 	<ul style="list-style-type: none"> • Participation level <ul style="list-style-type: none"> • Community-led initiative that designs and implements health promotion projects, activities, and workshops (eg, implementing benches along walking paths, workshops regarding positive health, and developing health promotion apps; nearly disbanded, but continued). 	<ul style="list-style-type: none"> • Participation level <ul style="list-style-type: none"> • Community-led initiative continued but with different citizens involved at the governance level. In addition, the community-led initiative was also being supported by a public health professional (ongoing).

^aPPI: patient and public involvement.

Following on, the paper will also examine participants’ underlying experiences throughout the CE process (including enabling and constraining experiences and support needs to further develop CE). The study indicated another 4 overarching themes related to these experiences:

- Theme 4: lack of investment in the engagement environment
- Theme 5: need for facilitative leadership
- Theme 6: need for a clear and shared vision underscoring the importance of CE
- Theme 7: misalignment between citizens’ and professionals’ perspectives and motivations for CE

Throughout this section, examples of CMOs will underpin the results, and further CMO examples can be found in [Multimedia Appendix 3](#).

Changes in Applied CE Approaches

Overview

Within all 6 regions, there had been changes within both the organizationally led CE projects and community-led initiatives. [Table 2](#) shows a summary of CE approaches that have been implemented over the past 4 years within the 6 regions to improve communities’ health and well-being and to improve

the health and care systems. This summary is not an exhaustive list, and the final column is focused on newly implemented CE approaches compared to previous years. [Table 2](#) highlights that after 4 years, most approaches and underlying activities could still be classified at the “consultation,” or “communication” level and that some “participation level” approaches within the regions had been disbanded (ie, the web-based community platform in region A, the client council in region D, and the policyholder cooperation in region E). Furthermore, although this list is not exhaustive, the results as shown in [Table 2](#) seem to underscore that the implementation of CE in the regions is in development and that most CE initiatives are now small scale. Though some of the regions were trying to address this, for example, the patient and public involvement organization in region B had been trying to embed CE within organizational cultures through training, and the organization in region A had been trying to build relationships with engaged citizens.

Theme 1: From Regional Focus to Community Focus

[Table 2](#) also highlights that the 6 regions have adapted their CE approaches over the past 4 years. First, some regions had shifted their CE approaches from having a more regional focus to a community-based focus. For example, the policyholder cooperation in region E had been disbanded as its focus on complicated, regional issues such as the regional economy and the viability of the hospital was seen as too far removed from “average” citizens’ lived experiences. That is why, at the time of interviewing, the regional board was looking for ways to take a more community-focused approach by involving and facilitating citizens in practical health promotion activities aimed at improving the health and social cohesion of communities, thus hoping to connect more with the lived experiences of citizens and communities.

Theme 2: Building Relationships With (Already Engaged) Citizens

Second, and likely relatedly, some regions were trying to change their CE approaches to focus more on building relationships with communities and engaged citizens. For example, policy makers in region A have noticed a slow shift in mindset within municipalities. Where originally municipalities thought they knew what was best for communities, policy makers (through positive experiences of involving citizens in developing and renewing social spaces) are seeing the benefit of building relationships with (engaged) citizens and communities and involving citizens in the design phases of projects, instead of presenting finalized plans to citizens.

Theme 3: Shift to More Practical and Tangible Projects

Third, and again likely relatedly, most of the regions have started focusing more on practical, tangible CE projects with activities aimed at improving the health and social cohesion of communities (eg, placing benches in parks to encourage older residents to go for walks, walking groups, and living library events; [Table 2](#)). For example, the citizens within the community-led initiative in region F had organized many smaller-scale practical projects and events as the tangible aspects of health promotion and social cohesion activities were seen as

more motivating than, for example, the development of a web-based app for individual use:

It's not for nothing that things [CE] start in the villages...It's got to do with the small scale that makes people want to self-organise and maybe it helps with the collaboration, it's]always easier with knowing people and after that maybe there's the right energy whereby people want to do stuff [get engaged/self-organise]. So that smaller scale, always has something to do with it. [Region F, policy maker, male]

Citizens' and Professionals' Experiences

Underlying the nature of changes in the CE approaches, as described in the previous section, were citizens' and professionals' experiences ([Multimedia Appendix 3](#)). Overall, citizens and professionals had experienced many of the previous approaches as too far removed from citizens' lived experiences to be successful and felt that further improvements were necessary to further develop CE.

Theme 4: Lack of Engagement Environment

First, and most prominently, both citizens and professionals had experienced a lack of investment in, and a need to improve, the engagement environment. This lack of investment prevented CE from being fully embedded within organizational cultures. Both citizens and professionals experienced the need for further investments, that is, in the form of resources and funding for activities and initiatives, staff with CE skills and know-how, and space and time to build relationships with a wider range of citizens and to innovate CE approaches ([Multimedia Appendix 3](#)). The study indicated that participants experienced the need for 2 different types of investment. The first type was a “softer,” more cultural type of investment. For example, in regions A and C, the organizational culture used to be that the municipalities decided everything, but because of laws such as the Participation Act (2015) and the Living Environment Act (2021), they have been forced to review the role citizens have (context). Furthermore, the newer generation of policy makers has been trained to see the value of CE and has experienced the positives of involving citizens in projects and policy making (context). Because of this, policy makers are increasingly seeing and believing the value of CE and at the same time experiencing that this belief is not supported by the wider municipality or their management (mechanism). They felt this slows down the cultural change required within organizations to enable successful CE approaches (outcome). At the same time, participants also described the more “tangible” types of investments required to enable the further development of CE approaches. For example, the community-led initiative in region F was able to organize health promotion and social cohesion activities successfully, despite the fact that organizations had not provided long-term financial support (context) and despite a drop in the number of volunteers (context). The volunteers experienced the organization of such activities as draining without support as it cost them a lot of time and energy (mechanism). This made it difficult for the community-led initiative to ensure they could keep organizing such activities in the long term (outcome). While one of the organizations in

region D highlighted the need to develop CE skills and know-how. For example, one of the organizations had applied for a subsidy to involve organizations from the cultural or creative sector to develop new and innovative ways to involve citizens within the Positive Health Network (context). Because when health and care organizations think about CE, they end up involving citizens in the traditional (more limited) way (mechanism). Unfortunately, the subsidy was rejected, which meant that the search for new innovative ways to involve citizens remains (outcome):

I think I've been lucky in certain ways, that our conservative local councillor left and a new councillor took his place. And that new councillor said to me: "why don't you just try something." If I'd still had a councillor who kept saying: "no, that's not how we do it." Then I wouldn't have had the space to involve the citizens like that. [Region A, policy maker, male]

My story, what are the blockades? I see that in the community and for the community-led initiative a lot of balloons [projects] are raised. Sometimes with a small pot of money. But when that pot of money is emptied, the balloons are popped. There's too little space for embedding things. [Region F, citizen, female]

Theme 5: Need for Facilitative Leadership From Organizations

Second, and relatedly, both citizens and professionals had experienced a lack of, and need to provide and receive, facilitative leadership. Furthermore, both citizens and professionals were also trying to develop new leadership. For example, the community-led initiative in region F was launched 5 years ago with a local health care professional in the lead but without a clear governance or leadership structure (context). Initially, 4 board members were selected but most were health care professionals within the community as well (and were thought to have vested interests removed from "regular citizens"; context). Citizens felt these members were unapproachable and the health care professional who had launched the initiative was not motivated to take up the leadership role in the long term (mechanism). This lack of clear leadership made it difficult for the engaged citizens to know what the decision-making process was or who to turn to with their project ideas (outcome). That is why when the members of the old governance board left, the new members (all citizens) decided to be approachable and discuss and align everyone's goals clearly. An example of how professionals were experiencing CE was expressed by policy makers in region C. The negative experiences of involving citizens when the municipality had already developed the plan meant they started searching for a new approach to CE (context). The new approach is based on sharing the problem and issues the municipality is trying to address with communities with the aim of improving the collaboration between engaged citizens and organizations (context). Sharing the problem fosters commitment among engaged citizens and organizations, motivating them to consider potential solutions (mechanism). Through this new, more facilitative approach, everyone

(municipality, engaged citizens, and organizations) has gained more understanding of each other (outcome):

I think you need leadership and guts, you have to be able to reach out to citizens and to show that you can let go [of control]. Several of our administrators find that difficult. They're used to being in charge and in control. But actually, here we say "don't be in charge or in control, but ask questions. Create and connect. That's a totally different way of providing leadership." [Region E, local councilor, male]

I think that you just have to talk to each other, what you want from the initiative, as professional and as volunteer. You have to create the atmosphere where such things can be talked about, and both sides have to listen...that requires that you make yourself vulnerable thus open to the ideas, suggestions and comments of others. [Region F, citizen, male]

Theme 6: Need for a Clear and Shared Vision Underscoring the Importance of CE

Third, both citizens and professionals continued to seek and emphasize the need for the implementation of a clear and shared vision underscoring the importance of CE. Policy makers in region A highlighted that old habits of policy makers of not sharing control with citizens die hard, especially as there is not a clear or shared vision for the relevance of CE within the municipality (context). The lack of shared vision has prevented policy makers from experiencing and seeing CE as part of their "day-to-day" business (mechanism). That is why the required culture change to embed CE activities within organizations and on a regional level successfully has taken a long time (outcome). Some policy makers speculated that this lack of CE vision is because municipalities only involve citizens (through the bare minimum effort) because national policies such as the Participation Act (2015) have dictated they do so, instead of CE being part of a wider belief in how policy making should also be based on CE. This need for a shared vision was also experienced by the community-led initiative in region F. The remaining volunteers and the support worker started looking for what their next steps and new aims should be after the old governance board had left and the initiative was nearly disbanded (context). As the community-led initiative had nearly collapsed, it created a sense of urgency and commitment with the remaining volunteers to continue the initiative (mechanism). At the same time, they experienced it as difficult to rise above the failings and negative experiences (to "let go off the old ballast"; mechanism). This meant that they had not yet succeeded in developing a new vision and that they were still searching for a vision that could act as the connecting thread for the initiative (outcome):

It's also about the colleagues...It matters how the process is handled and by who. There's quite a big differences in that. We don't have one clear view, vision or policy of "it's in this way that we do CE or CE is always important in this phase of a project." Of course CE is not a one-size-fits-all approach, but unknown makes unloved, I think. There's so many

people whereby CE is not part of the process. [Region A, policy maker, male]

Theme 7: Misalignment Between Citizens' and Professionals' Perspectives and Motivations for CE

Fourth, and related to the lack of a shared vision, citizens and professionals had experienced a misalignment between citizens' and professionals' perspectives and motivations for CE and thus had different experiences throughout the process of CE. Citizens and professionals had experienced this lack of alignment in both organizationally led CE approaches and community-led initiatives. The citizens stated that they felt that professionals were too outcomes focused. For example, the community-led initiative in region F was in transition and was searching for which aims and activities should be continued and taken up (context). Engaged citizens and professionals had differing goals and ambitions (context). Professionals were more outcome focused, which citizens felt like made the initiative aim too high (mechanism). Citizens meanwhile were engaged because of their intrinsic motivations and because they wanted to increase their social connection within the community (mechanism). Such differences in aims should be openly discussed (outcome). Professionals in region D speculated what was underlying this misalignment. With CE approaches, everyone (citizens, professionals, and volunteers) involved has their own language, interests, and scope (context). Citizens often think and operate "on a smaller," "community-based" level (context). Professionals become irritated because, from their perspectives and aims, they feel change is not happening fast enough (mechanism). The professionals felt this showed that motivations between citizens and professionals were not aligned and that resource investments (especially time and space) should be created to discuss these differences and to address the motivations and interests of citizens more specifically (outcome). This is comparable with citizens' experiences who had also underscored the importance of creating a transparent dialogue between citizens and professionals to align the motivations:

Differences in interests...You have to have a shared goal. [Region F, citizen, female]

Reference Panel Deliberations

Panel members recognized the findings and stated they had also found it easier to involve citizens with local approaches, which were more aligned with citizens' lived experiences. Furthermore, both citizens and professionals within the panel also underscored their search for new collaborative forms of working between citizens and organizations and how to best involve citizens in the decision-making process. For example, they were searching for ways to enable some citizens to be involved in the long term (mostly in governance structures) and at the same time allow other citizens to be involved in the short term (without too much investment of their time and effort). The panel also discussed important enablers to work toward these new ways of collaborative working for CE. For example, both citizens and professionals within the panel highlighted that one of the most important enablers was having leadership who can create support and garner interest for CE. The professionals particularly highlighted that such leadership would help to change the culture

within organizations, for example, ensuring citizens are not involved because this has been decreed top-down (eg, through the Participation Act 2015 and Living Environment Act 2021) but because there is a sincere belief and hope within the organization to ensure services and policies are better aligned to citizens' and communities' needs and experiences. They also underscored the significant importance of a clear vision and corresponding plan for CE, for example, who should be involved, when, where, and about which topics. Finally, both citizens and professionals within the panel stated the importance of long-term investments to properly embed CE within their organizations or their neighborhoods. Citizens especially underscored their need to have organizations (health and care organizations and local and regional governments) invest financially within their initiatives in the longer term, whereas professionals stated that they needed the time and space to be able to innovate CE—not merely through financial investments but by being given more time and space to involve citizens and to experiment with new CE approaches and activities.

Discussion

Principal Findings

Using the RE approach, this multiple case study investigated how CE approaches in 6 different Dutch regions have changed over the past 4 years. It also investigated citizens' and professionals' underlying experiences impacting these changes. The results have shown that CE approaches are changing from having a region-wide focus to a more community-based focus, to building relationships with engaged citizens, and to focusing more on practical health promotion activities (rather than "abstract" topics such as the redesign of regional hospitals). The results of this study also suggest that CE (including the underlying understanding of how to develop and implement CE successfully) still has not been embedded within organizational cultures. This has arguably meant that the remaining CE approaches seem to be operating on a smaller scale (instead of using a mix of smaller scale and more regional approaches; Table 2) and that professionals and citizens required further investments in the engagement environment, the need for facilitative leadership, and the need for a shared vision on how to act upon CE based on aligned motivations.

Deductively analyzing the results showed if and how the guiding principles [13,14] (described in the *Methods* section) were being considered and applied within the 6 regions. The guiding principle that professionals were particularly concerned with was principle 1, which pertained to leadership. Professionals were aware that they needed to develop their facilitative leadership toward citizens and also required more supportive leadership from their organizations to better embed CE within projects and organizations. Broadly speaking, although many of the interviewed professionals observed and believed in the benefits of CE, they felt that their management largely did not. They felt this prevented the proper embedding of CE within organizational cultures and also hindered them from involving citizens as early as possible (principle 3) and often prevented them from sharing decision-making control with citizens (principle 4). Furthermore, citizens within this study often

discussed the importance of open and transparent dialogue between citizens and professionals regarding their motivations and aims for CE approaches (principle 8). As Beresford [10] suggests, CE in health has been shaped by the political agendas of (national and local) politicians, policy makers, and professionals, and Willems [31] has shown that efficiency and effectiveness are important underlying CE aims for organizations, which has made it harder for organizations to deploy resources to improve and develop CE. Similar to previous studies, this study has shown that CE approaches (only) focused on organizational (regional and more abstract) aims largely failed to motivate citizens to become involved [11,13,14,32]. By openly discussing these aims and providing the space and leadership to communities to share their aims, CE approaches can hopefully better address citizens' aims as well.

Relatedly, an important principle that participants had recognized and experienced as an important barrier but had not yet actively invested in was principle 9 regarding the development of a shared vision for CE. This may well be related to the experienced lack of supportive leadership and dialogue (between citizens and professionals), as described above. For example, citizens highlighted the importance of articulating achievable goals and highlighted the importance of transparently discussing any differences in aims. While professionals had experienced a lack of time to formulate clear and achievable goals for CE projects—perhaps because management felt like CE has been forced upon them by national policies like the Participation Act (2015) and the Living Environment Act (2021) as some professionals within this study had theorized.

Relatedly, one of the reasons for this lack of transparent dialogue between citizens and professionals regarding a CE vision could be the fact that both citizens and professionals described a lack of investment in the engagement environment as an important barrier. Such findings are in line with previous studies, such as the study by Holley [14], which has shown that many current engagement environments are built for efficiency, rather than, for example, building relationships with not-yet engaged or harder-to-reach groups. Such an engagement environment often results in a loss of influence for citizens, especially those who are socioeconomically disadvantaged [14]. This finding is further underscored by the fact that very few of this study's participants had discussed experiences regarding the addressing of power imbalances (principle 5) or had discussed experiences regarding the need to develop safe and trusting environments for citizens to enable citizens' involvement (principle 2). This study's participants highlighted the importance of properly embedding CE, for example, by making CE a structural and routine part of projects and policy development; by providing citizens and professionals with the time and space to develop creative engagement approaches; by providing community-led initiatives with long-term financial support; and by helping professionals to develop CE skills and know-how, for example, by providing training and guidelines.

This lack of investment in the engagement environment, leadership, and shared vision (based on aligned citizens' and professionals' motivations) may well have led to organizations in the 6 regions choosing to shift from a regional approach to

a community-based focus and shifting their focus from more complex regional topics to more tangible projects, instead of trying to bolster and improve the original approaches (through such investments) and at the same time also build relationships with communities and supporting more tangible projects. Arguably the different types of CE approaches (ie, regional, focused on complex issues such as the reconfiguration of health care services, community-based and focused on building relationships with communities, and focused on health promotion activities) should be applied alongside each other. Building relationships with citizens will also help to ensure CE approaches are better aligned with citizens' lived experiences and motivations. Prior literature indicates that citizens exhibit diverse interests and preferences for involvement, ranging from engaging in practical activities and providing peer support to participating in policy-making processes to ensure that policies better reflect their lived experiences [32,33]. To enhance citizens' more active participation in the development and delivery of health and care services, an investment is required to develop various types of approaches beyond the currently defined roles [16,17].

Despite the fact that this study indicates a systemic lack of investment in CE, this study also offers hopeful signs. First, Table 2 only shows the CE approaches that have been implemented and does not show potentially positive underlying (cultural) changes. For example, 1 citizen in region A described that they felt more collaboration was taking place between organizations and client councils. Furthermore, professionals within this study suggest that newer policy makers and professionals have been trained to believe in the value of CE and want to investigate new and more collaborative ways of working with communities and citizens. Not only has this newer generation been trained to believe in citizens' and communities' rights to be involved but also their CE experiences (with more local approaches) have shown them the benefits of involving citizens, for example, ensuring that policies are more aligned with citizens' own experiences and needs [15]. Furthermore, this study's findings also indicate ways to improve the engagement environment and to further develop CE. CE should be supported by a flexible system rather than bureaucratic systems and processes, which should be underpinned by a variety of creative CE approaches, sufficient resources (ie, know-how, time, and finances), and an organizational culture that maintains CE as "business as usual" for all projects. These findings suggest that a new guiding principle should be formulated regarding the different ways in which a supportive engagement environment can be implemented. More research is required to properly formulate this new guiding principle, though the results of this study show that such a principle should underline 3 different but interrelated aspects of CE. A supportive engagement environment requires (1) structural investment, including staff with CE know-how and skills, finances, and time and space to develop creative CE approaches; (2) facilitative leadership within and for communities and organizations; and (3) a clear and shared CE vision (based on alignment of citizens' and professionals' motivations). There is a circularity to the 3 aspects that makes it harder for organizations to know where to start when (further) developing their CE approaches. For example, leadership and an investment of resources may be

required to create a shared vision for CE. However, a shared vision is also required to leverage sufficient resources and leadership at different levels within organizations and communities. Ultimately, this study suggests that without such investments, it will be challenging to fully integrate CE into organizational cultures and to transition CE from being perceived merely as a beneficial addition to health and care systems to being recognized as essential for enhancing transparency, accountability, equity, and person-centeredness within those systems.

Limitations

One limitation is the relatively small number of participants, especially engaged citizens, for the primary data source (T4). Unfortunately, the first COVID-19 wave may have prevented more participants, working and volunteering in the health and care system, from taking part. This limitation was mitigated by the fact that this study tracked the CE approaches being implemented for 4 years and by the reference panel's workshop discussions as this confirmed the validity and applicability of our interview findings in other contexts, thus further validating and enriching the interview findings. Another COVID-19-related limitation was the fact that interviews had to take place on the web or over the telephone; this prevented participants from fully reviewing their storyboards and areas for further development of CE.

Future Studies

This case study indicates the importance of a supportive engagement environment created by structural investments, including staff with know-how and skills, finances, and space to develop creative CE approaches; facilitative leadership within and for communities and organizations; and a clear and shared overarching vision for CE based on the alignment of citizens' and professionals' motivations. However, future studies are required to further unpack these aspects of CE and to highlight how to practically apply these aspects for the improvement of CE. For example, future studies could focus on how to create

a transparent dialogue between communities and organizations to align communities' and organizations' aims for CE. Future studies could also examine different (and more practical) ways in which the engagement environment can be improved and supported by organizational management and regional and national governments.

Conclusions

This study investigated how CE approaches had changed over the past 4 years in 6 different regions in the Netherlands. It examined citizens' and professionals' experiences underlying these changes, including the barriers, enablers, and support needs. The study showed three overarching themes along which CE had been adapted: (1) moving away from regional CE approaches; (2) focusing on building relationships with already-engaged citizens and communities; and (3) focusing on practical, tangible health promotion activities (instead of more complex "abstract" programs). Furthermore, participants had experienced (1) a lack of a supportive engagement environment, (2) a lack of facilitative leadership, (3) a lack of a shared vision for CE, and (4) a misalignment in citizens' and professionals' aims. The study suggests that citizens and professionals perceive and experience CE differently and that they have different priorities for CE. To enable and support the further development of CE approaches, both citizens and professionals experienced the need for investments in the engagement environment (eg, through more structural organizational support, time, and space to innovate and improve CE approaches and to embed CE within organizational cultures), for more facilitative leadership, the need to develop a shared vision, and the alignment of citizens' and professionals' motivations. Such investments and changes to organizational cultures, structures, and processes would enable organizations to be more open and sensitive to the different ways in which different citizens want to be involved. Without such further investments and leadership, CE will remain seemingly smaller scale and piecemeal, instead of being seen as crucial to restoring accountability and person-centeredness to health and care systems.

Data Availability

All data generated and analyzed during this study are included in the published article and supplementary information files. Templates used for data extraction and analysis are available from the corresponding author on reasonable request.

Disclaimer

Consent for publication was obtained from all the study participants. Participants were provided with information letters and were also verbally informed of the fact that any information they shared would be treated completely confidentiality and anonymously (eg, without any person-identifiable information). This is in accordance with the Dutch national guidelines.

Authors' Contributions

EdW participated in conceptualization, methodology, formal analysis, investigation, writing the original draft, and reviewing and editing the final draft. HD participated in conceptualization, methodology, reviewing and editing the final draft, and supervision. KL participated in conceptualization and review and editing. CB participated in conceptualization, methodology, reviewing and editing the draft, supervision, and funding acquisition.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Realist evaluation standard reporting form.

[\[DOCX File , 33 KB - jopm_v16i1e47500_app1.docx \]](#)

Multimedia Appendix 2

Reference panel participants' description.

[\[DOCX File , 27 KB - jopm_v16i1e47500_app2.docx \]](#)

Multimedia Appendix 3

Summary of the context-mechanism-outcomes underpinning themes.

[\[DOCX File , 56 KB - jopm_v16i1e47500_app3.docx \]](#)**References**

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Abbreviations

- CE:** community engagement
CMO: context-mechanism-outcome
RE: realist evaluation

Edited by M Hudson; submitted 22.03.23; peer-reviewed by AB Kennedy, N Mungoli; comments to author 07.05.23; revised version received 30.10.23; accepted 12.11.23; published 15.05.24.

Please cite as:

de Weger E, Drewes H, Luijkx K, Baan C

Tracking the Development of Community Engagement Over Time: Realist Qualitative Study

J Particip Med 2024;16:e47500

URL: <https://jopm.jmir.org/2024/1/e47500>

doi: [10.2196/47500](https://doi.org/10.2196/47500)

PMID: [38748458](https://pubmed.ncbi.nlm.nih.gov/38748458/)

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Original Paper

Suicide Prevention by Peers Offering Recovery Tactics (SUPPORT) for US Veterans With Serious Mental Illness: Community Engagement Approach

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Abstract

Background: Peer specialists are hired, trained, and accredited to share their lived experience of psychiatric illness to support other similar individuals through the recovery process. There are limited data on the role of peer specialists in suicide prevention, including their role in intervention development.

Objective: To better understand peer specialists within the Veterans Health Administration (VHA), we followed partnership community engagement and a formative research approach to intervention development to (1) identify barriers, facilitators, and perceptions of VHA peer specialists delivering a suicide prevention service and (2) develop and refine an intervention curriculum based on an evidence-informed preliminary intervention framework for veterans with serious mental illness (SMI).

Methods: Following the community engagement approach, VHA local and national peer support and mental health leaders, veterans with SMI, and veteran peer specialists met to develop a preliminary intervention framework. Next, VHA peer specialist advisors (n=5) and scientific advisors (n=6) participated in respective advisory boards and met every 2-4 months for more than 18 months via videoconferencing to address study objectives. The process used was a reflexive thematic analysis after each advisory board meeting.

Results: The themes discussed included (1) the desire for suicide prevention training for peer specialists, (2) determining the role of VHA peer specialists in suicide prevention, (3) integration of recovery themes in suicide prevention, and (4) difficulties using safety plans during a crisis. There were no discrepancies in thematic content between advisory boards. Advisor input led to the development of Suicide Prevention by Peers Offering Recovery Tactics (SUPPORT). SUPPORT includes training in general suicide prevention and a peer specialist-delivered intervention for veterans with SMI at an increased suicide risk. This training aims to increase the competence and confidence of peer specialists in suicide prevention and the intervention supports veterans with SMI at an increased suicide risk through their recovery process.

Conclusions: This paper intends to document the procedures taken in suicide prevention intervention development, specifically those led by peer specialists, and to be a source for future research developing and evaluating similar interventions.

Trial Registration: ClinicalTrials.gov NCT05537376; <https://classic.clinicaltrials.gov/ct2/show/NCT05537376>

(*J Particip Med* 2024;16:e56204) doi:[10.2196/56204](https://doi.org/10.2196/56204)

KEYWORDS

suicide prevention; advisor; veterans; recovery; community; peer specialist; peer support; serious mental illness; participatory design; community engagement; lived experience

Introduction

Suicide prevention is the top priority for the US Department of Veterans Affairs (VA). The 2023 National Veteran Suicide Prevention Annual Report described increases in veteran suicides between 2020 and 2021 [1]. Moreover, certain groups remain at high risk for suicide. For example, veterans with serious mental illness (SMI, eg, psychosis and bipolar disorders) have more than twice the rate of suicide and death ideation compared with nonveterans with SMI [2] and higher suicide rates compared to the general US and veteran populations [3]. Among veterans who recently used Veterans Health Administration (VHA) services, veterans with bipolar disorder had increased rates of suicide deaths from 2001 to 2021 [1], while those with schizophrenia had increased rates from 2019 to 2020 [4] but an overall decrease in suicide deaths from 2001 to 2021 [1]. All these individuals interacted with the VHA. As such, the VHA may be an ideal space to intervene and prevent future suicides.

There may be a limit to impact and usefulness of current suicide prevention standards of care for those with SMI. In a review of trials with suicide outcomes, researchers found that 61.7% of all trials and 75% of psychotherapy trials *excluded* individuals based on psychosis [5]. Relatedly, those with SMI are difficult to engage in and retain in treatment [6], experience cognitive impairments [7-11], and have limited social supports [12-15]. Therefore, veterans with SMI are an important high-risk group to target for suicide prevention interventions tailored to their unique needs.

An overarching emphasis for psychosocial treatments for SMI in the VHA is “recovery,” a process of change in which individuals strive to build a fulfilling life regardless of challenges stemming from mental health conditions [16]. A vital aspect of the recovery model is the importance of peer support, a nonmanualized form of social support in which people with similar challenges (eg, psychiatric and substance use disorders) help one another by sharing information and perspectives, helping develop problem-solving skills, and serving as successful role models [17].

Peer specialists are individuals who are certified and trained to use their own lived mental health experiences to support others through the recovery process and are paid or unpaid employees of the mental health system [18]. In VHA, peer specialists must be veterans themselves, and the ~1400 currently employed VA-wide are considered a vital part of VHA mental health recovery services [19]. VHA peer specialists are available to work with veterans once they are connected to care and provide recovery-oriented support as an adjunctive service; peer specialists may also provide outreach to veterans not enrolled

in VHA. VHA peer specialists’ scope of practice includes modeling recovery and engendering hope, supporting active engagement in treatment, providing step-down recovery support, encouraging skill use, helping veterans advocate for themselves, and connecting veterans to VA and community resources [19]. Recent reviews of peer support services both in and out of VHA have documented a variety of positive outcomes for service users with SMI (eg, reduced inpatient use and improved recovery, hope, empowerment) [18,20], although some studies found little to no impact on outcomes [18,20,21]. Conclusions from these reviews highlight the need for increased methodological rigor in studies including peers.

Peer specialists are a potentially promising but untested adjunct to clinician-delivered suicide prevention. A recent review of peer specialist–based suicide prevention approaches concluded that they are feasible, including no major negative effects [22]. Peer specialists can address hopelessness, shame, burdensomeness, and social isolation, all psychosocial factors associated with suicide risk according to the interpersonal theory of suicide [23]. VHA peer specialists can screen for suicide but are not permitted to conduct comprehensive risk assessments. Furthermore, in VHA, peer specialists are already often working with individuals at high risk for suicide [24]. For example, data from a recent review of all services provided by all VHA peer specialists showed that 8% of the veterans they work with had a “high-risk suicide flag” on their medical record [25]. Qualitative data from peer specialists and clinicians working in a civilian suicide aftercare program indicate that peer specialists positively value working in suicide prevention [26]. Therefore, there is a need to improve the methodological rigor of peer support for SMI as well as systematically develop peer-delivered interventions to decrease suicide risk.

To create a peer-delivered suicide prevention intervention, we applied a formative research approach to intervention development [27]. The primary focus was including veteran peer specialists’ input to allow for equal decision-making with academic researchers in the intervention development [28,29]. We focused on potential role challenges that VHA peer specialists may experience in suicide prevention, including the recovery model of mental health and the intersection with other suicide prevention best practices. In this paper, we describe the results of a series of advisory meetings with the aims to (1) identify barriers, facilitators, and perceptions of VHA peer specialists delivering a suicide prevention service and (2) develop and refine an intervention curriculum based on an evidence-informed preliminary intervention framework.

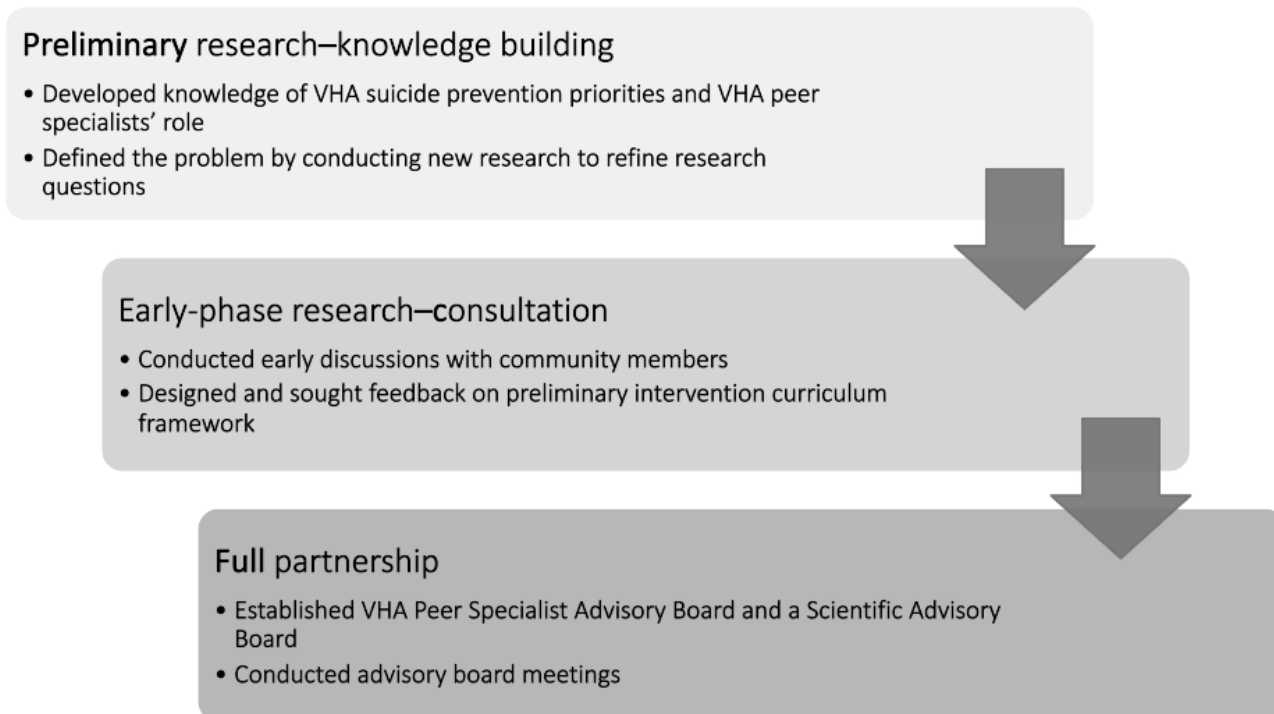
Methods

Study Design

This overall study design is a combination intervention

development approach [27] with a specific focus on a partnership through community engagement [29]. Figure 1 displays the methodological process of this study and is in chronological order unless otherwise specified as part of an iterative process.

Figure 1. Methodological process of community-engaged partnership intervention development approach. VHA: Veterans Health Administration.



Ethical Considerations

The VA San Diego institutional review board (IRB approval H210132) approved the larger research trial in which this paper reports on the initial phase (ClinicalTrials.gov NCT05537376). All advisors provided verbal informed consent. No monetary compensation was provided for participation.

Preliminary Research—Knowledge Building

Developed Knowledge of VHA Suicide Prevention Priorities and VHA Peers Specialists' Role

In this approach, we first identified gaps in current suicide prevention interventions and standards of care, including understanding the current state of the literature (as documented in the Introduction section), intervention development methodology among those with lived experience [30-32], and community-engaged research to inform intervention development [29,32]. Next, the principal investigator (PI, SAC) held a series of informal discussions with various VHA local and national peer support and mental health leaders, which highlighted encouraging support for VHA peer specialists to be involved in suicide prevention efforts while remaining inside their scope of practice. Simultaneously, the PI sought out and established relationships with scientific experts in suicide prevention, SMI, peer support services, and intervention design. These experts were identified as leaders in their fields by recommendations by others the PI spoke with and some were previously known to the PI. Experts in all areas echoed the same message as VHA leaders. SMI experts specifically emphasized

considering cognition when tailoring interventions for individuals with SMI or anyone in an emotional or suicidal crisis. To date, compensatory cognitive strategies [33,34] have not been used to improve learning and recall in the context of suicide prevention interventions but may be crucial as cognitive impairments may limit the ability to recall and engage in preventive behaviors and intervention strategies.

Defined the Problem

Preliminary research, based on the new knowledge acquired, was then conducted. This research focused on further understanding the important role of safety planning (ie, a 6-step plan collaboratively completed with a provider and a veteran to identify when the veteran is becoming suicidal and what specifically the veteran can do next [35,36]) as a suicide prevention intervention standard of care given the calls for future research on safety planning [37] and that many trials with suicide-related outcomes exclude individuals on the basis of psychosis [5]. This preliminary research found that increased social support is needed during a suicidal crisis [38,39], that veterans welcome the use of peers in suicide prevention care [40,41], and that improved ability to remember and use one's safety plan is needed [42-44]. Further conversations were needed to determine whether peers could enhance safety planning.

Early Phase Research—Consultation

Discussions With Community Members

Valuing veteran peer specialists' perspectives on their potential role in suicide prevention, the PI first met with a group of 5

veteran peer specialists across the country interested in providing input as identified by a community liaison expert. Then, the PI joined the monthly meeting of the 9 local VHA peer specialists via invitation from the local recovery coordinator. Across meetings, a major discussion point was “recovery planning,” the prime example being the Wellness Recovery Action Plan (WRAP) [45]. WRAP is a peer-delivered, evidence-based intervention for those with SMI. WRAP centers on identifying broad warning signs of mental illness, developing wellness or coping tools for functional independence, planning for day-to-day effective living within one’s community, and building a crisis and postcrisis plan. WRAP focuses broadly on mental health and shares aspects with suicide safety planning. Although no formal protocols have been tested to adapt recovery planning for suicidal crises, veteran peer specialists informally shared that they have successfully used WRAP with individuals who are suicidal. Given the added benefit of interventions that directly target suicidal ideation and behaviors [46,47], a suicide-focused, WRAP-inspired plan delivered by peer specialists would allow for a recovery-oriented approach to enhance safety planning for veterans with SMI.

Designed and Sought Feedback on Preliminary Intervention Curriculum Framework

Following these conversations, a preliminary intervention curriculum framework was designed. Core concepts included valuing recovery, using wellness tools broadly and when suicidal, setting recovery goals, daily planning development, and learning (ie, cognitive training) strategy identification. This first iteration was reviewed by a VHA peer specialist, and, with verbal consent, the VHA peer specialist then explored the core concepts with 3 veterans with SMI. Both the VHA peer specialist and the veterans with SMI shared that the core concepts were relevant and acceptable to discuss in a peer support appointment. Notably, the VHA peer specialist expressed increased comfort, competence, and confidence in suicide prevention care following review of this intervention framework. Local and national VHA leadership provided feedback on the intervention framework and study design in one-on-one meetings over the study planning period. Leadership feedback remained centered on keeping the service within a VHA peer specialist’s scope of practice.

Full Partnership

Established VHA Peer Specialist Advisory Board and a Scientific Advisory Board

Five of the 9 locally employed peer specialists approached agreed to formally participate on a peer specialist advisory board. These advisors were provided with an informational sheet and provided verbal consent for their participation. All advisors on this board were peer specialists employed by the VHA and provided peer support services in mental health-related clinics and outreach teams. Peer specialist advisors attended eight, 30- to 60-minute meetings via videoconferencing to discuss the 3 themes in aim 1.

Of the scientific experts who provided input in the knowledge development phase, 6 scientific advisors were approached based on the sustained relationship with the PI and the unique area of

expertise they championed. They all agreed to participate on the scientific advisory board. The scientific advisors included experts in suicide prevention, SMI, VHA peer support services and implementation, and intervention design and development. The scientific advisors attended one-on-one meetings with the PI and met regularly in small breakout groups every 3-4 months via videoconferencing. Each meeting focused on questions pertaining to the scientific advisors’ expertise area to best use that expertise to enhance the intervention and subsequent implementation.

Advisory Board Meetings

The PI moderated all advisory board meetings. Before each meeting, advisory board members reviewed the current intervention material. They could provide written feedback in addition to providing their verbal feedback during the meeting. Discussion questions were posed in the following predetermined key areas in each meeting: (1) scope of practice (eg, how would this intervention change or enhance a peer specialist’s duties?); (2) content (eg, what do you think about a person thinking about suicide setting long-term recovery goals?); (3) intervention design (eg, how many appointments should be provided to cover the material?); (4) suicide prevention interventions (eg, what role should safety planning play in the intervention?); (5) training (eg, how much background suicide prevention information should be provided?); and (6) study design (eg, what role do the peer specialists delivering the intervention play in relation to the research team?). Meetings were audio-recorded with verbal consent. Advisors were not given compensation due to the nature of funding available.

Reflexive Thematic Analysis Process

Observational notes were collected in real time by 2 research staff members who were in attendance and directly after the meetings by the PI. Audio recordings of the meeting discussions were transcribed. A reflexive thematic analysis process was used after each meeting [48,49]. One research staff member and the PI read a transcript to familiarize themselves with the data. Then initial codes of the first meeting’s transcripts for each advisory board were generated noting these codes using Word’s (Microsoft Corp) comment function. Discrepancies were addressed and then codes were collaboratively determined for the remaining meetings. Codes were added into Excel (Microsoft Corp) and organized by potential theme. Themes were then finalized. Intervention material revisions by the research staff included all feedback and were provided to advisors to review 1 month prior to the next meeting. This process was iterative and discussed with the full research team. The process for each subsequent meeting was repeated.

Results

VHA Peer Specialist Advisory Board Contributions

Overview

VHA Peer Specialist Advisory Board themes included (1) the desire for suicide prevention training for peer specialists, (2) determining the role of VHA peer specialists in suicide prevention, (3) integration of recovery themes in suicide

prevention, and (4) difficulties using a suicide safety plan during a crisis.

Desire for Suicide Prevention Training for Peer Specialists

Peer specialist advisors were unclear what they are “allowed” to do when working with an individual at high risk for suicide, specifically when that individual was already known to be at a higher risk; they desired training to address these uncertainties. The peer specialist advisors believed that they did not have the confidence and competence to work with someone who is at a high risk for suicide (eg, “I’m worried I won’t know what to do or say [when someone says they are suicidal].”).

Determining the Role of VHA Peer Specialists in Suicide Prevention

The peer specialist advisors were unclear of the role of their direct clinical supervisor when a veteran is already identified to be at an increased risk of suicide (compared with whether the risk was newly identified by the peer specialist, eg, “I’ve been told to just bring my supervisor in at any mention of suicide.”). At the same time, peer specialist advisors indicated that they felt that they could do more for a veteran at an increased risk for suicide instead of immediately bringing in a licensed provider (eg, their clinical supervisor) to address the risk (eg, via a comprehensive suicide risk assessment [48]) if they had the necessary training (eg, “I feel like I can do more for suicidal veterans, but I’m not sure what I am allowed to do.”). Peer specialist advisors believed that they should have more autonomy when it comes to working with veterans at risk for suicide (eg, “We can adapt to what is needed in the moment ... that’s what we’re best at.”). These advisors expressed interest in continued participation in future phases of study, including providing informed consent to deliver the intervention and to share their experiences.

Integration of Recovery Themes in Suicide Prevention

Unique skills peer specialists bring to a suicidal crisis are discussions of recovery and recovery planning (eg, “...I’ve been there and, even if I don’t have the exact same experience, I can still share my story to show that recovery is possible...”). A suicide-focused recovery plan was welcomed by advisors (paired with the appropriate suicide prevention training) as it (1) is within their scope of practice to complete a recovery plan with a veteran and (2) would provide them an intervention that is focused on suicide when they encounter a veteran at an increased suicide risk. Advisors agreed that this type of plan would be useful for veterans before and after a suicidal crisis, suggesting that this intervention could be for veterans at varying risk levels. Establishing rapport at the beginning of the interaction with veterans, focusing on strengths (eg, “specifically, reasons for living”), and modeling effective communication of suicidal thoughts were desired components to include in this intervention.

Relatedly, in developing the design of this intervention, advisors made a series of requests based on the recovery model. First, they asked for the intervention to follow a similar order as other recovery-oriented interventions they deliver in VHA, such as Whole Health. They stated that the general format should start with psychoeducation, move into inspiring hope, and then focus

on recovery goals and social connection through daily action planning. Advisors noted that they liked “the option to have multiple versions” of certain materials. For example, the veteran could choose what format they prefer to use for their learning strategies (eg, post-it notes and mobile phone calendar). Finally, the advisors recommended a “triage approach” of what intervention material to focus on first (ie, asking about suicide) and then a hierarchy of recovery topics to target next in each appointment.

Difficulties Using a Suicide Safety Plan During a Crisis

In discussing the current standards of care for suicide prevention, the advisors reported potential difficulties with using suicide safety plans during a crisis based on their own lived experience of using a safety plan. Advisors expressed needing something shorter (eg, “a reminder of just my main reason for living and whom I am going to call”), instead of a 1-page or longer document when in a crisis. Advisors also suggested that this shorter plan should be recovery- and strengths-focused as well as “pocket-sized.” Wallet-sized hard copies and digital phone backgrounds with the pertinent information were discussed to have options to meet the needs of varying veteran preferences. Advisors expressed that while veteran patient treatment manuals are helpful for some, the option of translating any curriculum to memorable subelements may be beneficial especially when in a suicidal crisis. Relatedly, they suggested strategies for reminding a veteran to engage with their plan (eg, “Have you ever thought about the use of cell phones or alarms to help people with their daily goals? It’s something I try to use because I’m really good at getting lost in my mind.”). Ultimately, they requested to not have safety planning play a direct role in the intervention except for reviewing the veteran’s safety plan with them if they indicated that they were at higher suicide risk following VHA mandates.

Scientific Advisory Board Contributions

The scientific advisors’ recommendations were consistent in many respects to the VHA Peer Specialist Advisory Board’s contributions. They echoed the desire for peer specialists to play a valued role in suicide prevention and supported suicide prevention and intervention training for peer specialists within VHA (ie, theme 1). The scientific advisors focused on the peer specialists’ scope of practice within suicide prevention (ie, theme 2), which shaped the overall study design and outcomes as well as the intervention curriculum. There were no discrepancies between the advisory board’s feedback on the intervention.

In determining the role of peer specialists within suicide prevention (ie, theme 2), scientific advisors discussed the boundaries of VHA peer specialists’ scope of practice to address suicide risk (eg, promoting hope but not providing comprehensive suicide evaluations) and concerns from national advisors regarding the protection of peer specialists in this work. Possible iatrogenic effects to the peer specialists were considered paramount. Scientific advisors suggested peer specialists already hired at VHA as part of the Mental Health Care Line to serve as the peer specialists delivering the intervention in the study. The basis of this suggestion was made on funding availability as well as to further illuminate VHA peer specialists’ roles on

site, clinic feasibility, and future broader implementation needs. However, including peer specialists as participants in the study was an ongoing point of debate. Some scientific advisors believed that peer specialists should be treated as any other member of the research team—and therefore not participants in the study. Other advisors as well as the local IRB requested peer specialists delivering the intervention to be considered participants (ie, provide informed consent and data) to better learn about potential iatrogenic effects of peer specialists delivering a suicide prevention intervention. To settle this, both sides of the argument were presented to the VHA Peer Specialist Advisory Board, and it was agreed that peer specialists already hired within VHA will be consented participants as part of the study design and documentation of their roles will be pertinent outcomes to the overall study.

In terms of intervention materials and navigating challenges of current standards of care in suicide prevention (ie, themes 3 and 4), scientific advisors focused primarily on the need for compensatory cognitive strategies to increase salience and recall of intervention materials. Similarly, they provided formatting recommendations for the veteran workbook.

Preliminary Curriculum

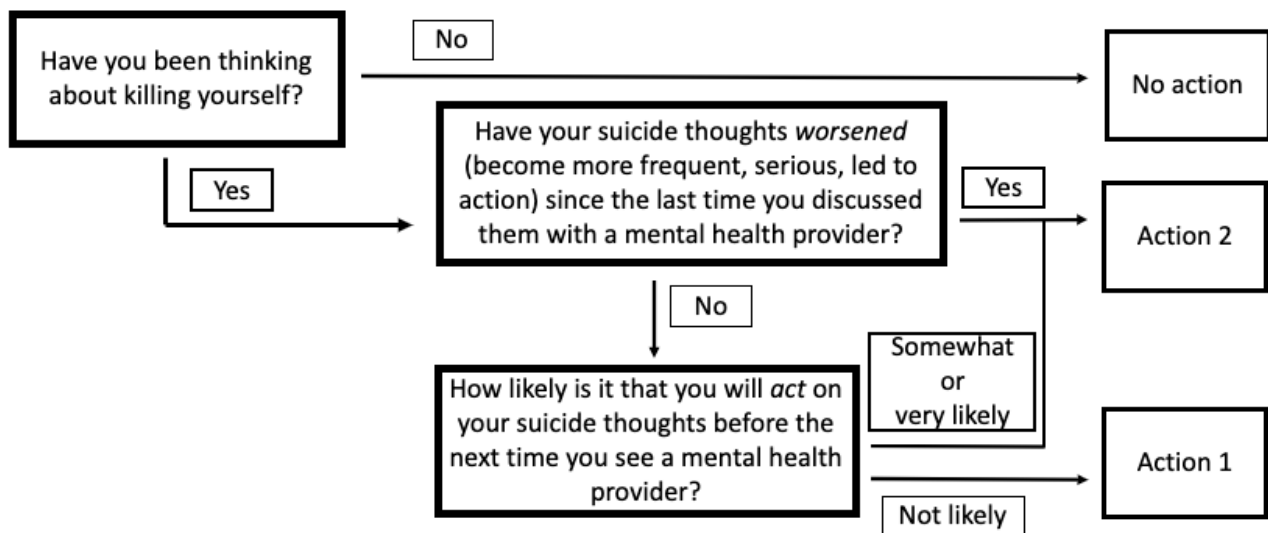
Overview

Based on the input from both advisory boards, we developed Suicide Prevention by Peers Offering Recovery Tactics (SUPPORT). The aims of SUPPORT are two-fold: (1) increase competence and confidence of peer specialists in suicide prevention and (2) assist veterans with SMI at increased suicide risk through the recovery process.

Training

The request for suicide prevention training by advisors led to the development of a training manual tailored to VHA peer specialists including two main sections: (1) a general suicide prevention training that can be a stand-alone training for any peer and (2) a training for VHA peer specialists in how to deliver a recovery-oriented, evidence-informed intervention for veterans with SMI at an increased suicide risk ([Multimedia Appendix 1](#)). The complete SUPPORT training includes two 4-hour training days. Adapting from other suicide prevention models for peer specialists [49], [Figure 2](#) demonstrates the procedure in which peer specialists can ask directly about suicidal thoughts and an algorithm for when to incorporate intervention by a licensed provider.

Figure 2. Peer specialist protocol for directly asking about suicidal thoughts and what to do next. PI: principal investigator.



No action = continue with the appointment.

Action 1 = review Veteran’s suicide safety plan with them, ensure they have contact information for their local regular mental health provider, the Veterans Crisis Line (988 press 1), and PI. Continue with the appointment. Inform PI after the appointment concludes.

Action 2 = alert on-call clinician (eg, PI) for further assessment with the person still present. You can complete Action 1 while waiting for on-call clinician.

Supervision and Consultation

As part of ongoing training, a study consultation group is also provided biweekly (timing based on the peer specialists’ request) after the complete SUPPORT training. The consultation group, comprising the peer specialists delivering SUPPORT, research staff, and a licensed clinical psychologist, serves as a dedicated time to discuss immediate concerns; receive feedback on SUPPORT appointments; discuss and process general concerns,

fears, and questions; and discuss implementation or other administrative topics.

Intervention Content

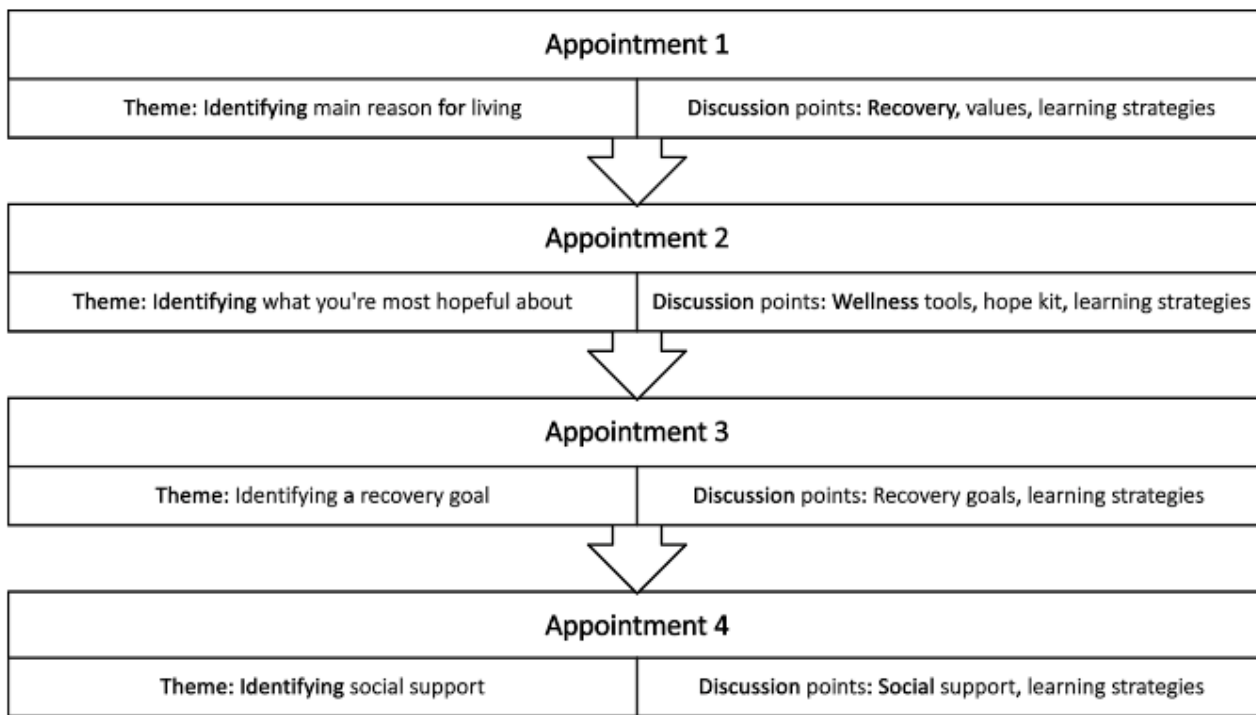
The SUPPORT intervention is designed to promote enhanced personal recovery, quality of life, and connectedness to foster effective management of veterans’ suicidal thoughts and behaviors ([Figure 3](#)). As is typical with other peer support services, the SUPPORT intervention augments and complements

ongoing care (eg, case management, individual therapy, and psychiatric medication appointments).

After completing a comprehensive mental health evaluation with a licensed VHA provider, the veteran will meet with their peer specialist for approximately four 50-minute appointments to discuss and mutually share elements of value-based living, recovery and action planning, and compensatory cognitive (ie, learning) strategies. Including learning strategies as part of the

SUPPORT intervention may improve learning of concepts, memory for intervention elements, prospective memory for symptom self-evaluations, review of intervention material, and promote general functional and social recovery. The final result is pocket-sized hard copy or digital set of 4 reminders for living (ie, the veteran’s main reason for living, what the veteran is most hopeful about, the veteran’s recovery goal, and who the veteran is going to call in a suicidal crisis).

Figure 3. Suicide Prevention by Peers Offering Recovery Tactics intervention preliminary intervention curriculum.



Discussion

Principal Findings

Over 18 months, the research team built trust and relationships with peer specialists and scientific advisors across the United States to design a suicide prevention intervention for veterans with SMI using the recovery model. Partnership engagement consisted of contacting potential partners via email to determine interest, building relationships with potential partners, creating 2 separate advisory boards, and meeting separately with both advisory boards to include their input and equal decision-making in the intervention development process. A peer specialist–delivered suicide prevention intervention and a suicide prevention training for VHA peer specialists were developed. This work adds to the literature of lived experience–driven intervention design and development in suicide prevention [30,31]. The steps reported here are intended to document the procedures taken in suicide prevention intervention development, specifically those led by peer specialists, and to be a source for future research developing and evaluating similar interventions.

Lessons Learned

This research paper depicts lessons learned, but 3 additional lessons are worthy of discussion. The first focuses on staffing.

Peer specialists, clinical supervisors, and leadership changes are necessary considerations in VHA training and intervention development work. This study saw turnover of local leadership, leading to delays in the community engagement process due to the uncertain structure of local peer support services. This process will continue to be carefully documented to support related work throughout the remainder of the study. Second, the research funding for this project precludes compensation of VHA employees for study activities. That is, peer specialists employed by VHA—the target population of advisors and deliverers of the intervention—were not eligible for study compensation. Other than monetary compensation, such as time off, should be considered. Third, limited models for advisor engagement exist [50], especially in suicide prevention intervention development [30,51]. Although there are relevant models to draw from in other areas [28,32,52], some of which focus on important diverse and underserved populations [53], and there is a need for clear documentation of partnership engagement in this intersection.

Limitations

While this study adds to the community engagement literature in suicide prevention intervention development studies, it has limitations. The advisory boards included a small number of individuals who were self-selected and, therefore, may differ from the larger population the study aims to serve. Due to IRB

constraints, the advisory board excluded veterans who were not peer specialists. To rectify this, veterans recruited as participants in the implementation phase will participate in qualitative interviews to include their perspectives in refining the intervention. Moreover, while initial advisors included veteran peer specialists outside of VHA, the final advisory board is made up of only VHA-employed peer specialists. Therefore, these findings may not generalize to other community or clinical settings where peer specialists are less common or may have different roles and levels of interaction with patients.

Conclusions

As Watling et al [30] suggested, a combined methodology is presented here. To further refine these materials, a 2-phase study

design that continues to involve these advisory boards is underway. In the remaining portion of phase 1, the research team will train VHA peer specialists via an open pilot trial and continue to monitor the role of the peer specialists as research team members and study participants. Individual semistructured qualitative interviews of the peer specialist and veteran participants will be conducted, and materials will be revised based on these interviews and ongoing input from both advisory boards. The open pilot trial of phase 1 is actively recruiting as of August 2023. This partnership approach to intervention development champions the crucial elements of including voices with lived experience of suicidal thoughts and behaviors in research design, testing, and implementation.

Acknowledgments

This work was supported in part by an award (IK2RX004239-01) from VA Rehabilitation Research and Development awarded to SAC. EWT gratefully acknowledges the support of a VA Rehabilitation Research and Development Research Career Scientist Award. The contents do not represent the views of the US Department of Veterans Affairs or the United States Government.

Conflicts of Interest

SAC discloses financial support from CAMS-care, LLC (a clinical training/consulting company), and from the Zero Suicide Institute. KLF discloses financial support from Social Wellness, LLC, and Emissary Health. MG discloses financial support from Boehringer Ingelheim Pharmaceuticals. There are no other conflicts of interest to disclose.

Multimedia Appendix 1

SUPPORT training manual preliminary curriculum for veteran certified peer specialists.

[[DOCX File, 29 KB - jopm_v16i1e56204_app1.docx](#)]

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Abbreviations

IRB: institutional review board

PI: principal investigator

SMI: serious mental illness

SUPPORT: Suicide Prevention by Peers Offering Recovery Tactics

VA: Veterans Affairs

VHA: Veterans Health Administration

WRAP: Wellness Recovery Action Plan

Edited by S Woods; submitted 09.01.24; peer-reviewed by J LaCroix, A Peeples; comments to author 22.02.24; revised version received 11.03.24; accepted 15.03.24; published 23.05.24.

Please cite as:

*Chalker SA, Serafez J, Imai Y, Stinchcomb J, Mendez E, Depp CA, Twamley EW, Fortuna KL, Goodman M, Chinman M
Suicide Prevention by Peers Offering Recovery Tactics (SUPPORT) for US Veterans With Serious Mental Illness: Community
Engagement Approach*

J Particip Med 2024;16:e56204

URL: <https://jopm.jmir.org/2024/1/e56204>

doi: [10.2196/56204](https://doi.org/10.2196/56204)

PMID: [38781010](https://pubmed.ncbi.nlm.nih.gov/38781010/)

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Original Paper

The Effect of Using a Client-Accessible Health Record on Perceived Quality of Care: Interview Study Among Parents and Adolescents

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Abstract

Background: Patient-accessible electronic health records (PAEHRs) are assumed to enhance the quality of care, expressed in terms of safety, effectiveness, timeliness, person centeredness, efficiency, and equity. However, research on the impact of PAEHRs on the perceived quality of care among parents, children, and adolescents is largely lacking. In the Netherlands, a PAEHR (Iuvenelis) was developed for preventive child health care and youth care. Parents and adolescents had access to its full content, could manage appointments, ask questions, and comment on written reports.

Objective: This study aims to assess whether and how using this PAEHR contributes to perceived quality of care from a client's perspective.

Methods: We chose a qualitative design with a phenomenological approach to explore how parents and adolescents perceived the impact of using a PAEHR on quality of care. In-depth interviews that simultaneously included 1 to 3 people were conducted in 2021. In total, 20 participants were included in the study, representing parents and adolescents, both sexes, different educational levels, different native countries, and all participating municipalities. Within this group, 7 of 13 (54%) parents had not previously been informed about the existence of a client portal. Their expectations of using the client portal, in relation to quality of care, were discussed after a demonstration of the portal.

Results: Parents and adolescents perceived that using Iuvenelis contributed to the quality of care because they felt better informed and more involved in the care process than before the introduction of Iuvenelis. Moreover, they experienced more control over their health data, faster and simpler access to their health information, and found it easier to manage appointments or ask questions at their convenience. Parents from a migratory background, among whom 6 of 7 (86%) had not previously been informed about the portal, expected that portal access would enhance their understanding of and control over their care processes. The parents expressed concerns about equity because parents from a migratory background might have less access to the service. Nevertheless, portal usability was regarded as high. Furthermore, both parents and adolescents saw room for improvement in the broader interdisciplinary use of Iuvenelis and the quality of reporting.

Conclusions: Using Iuvenelis can contribute to the client-experienced quality of care, more specifically to perceived person centeredness, timeliness, safety, efficiency, and integration of care. However, some quality aspects, such as equity, still need

addressing. In general, client information about the portal needs to be improved, specifically focusing on people in vulnerable circumstances, such as those from migratory backgrounds. In addition, to maximize the potential benefit of using Iuvenelis, stimulating a person-centered attitude among professionals is important. Considering the small number of adolescent participants ($n=7$), adding quantitative data from a structured survey could strengthen the available evidence.

(*J Particip Med* 2024;16:e50092) doi:[10.2196/50092](https://doi.org/10.2196/50092)

KEYWORDS

electronic health record; EHR; personal health record; child health services; child health; child welfare; adolescent health services; pediatrics; parent; care quality; perceived quality of care; patient experience; client perception; quality of care; parent; adolescent; patient portal; client portal; qualitative study

Introduction

Background

In the implementation and optimization of health care services, assessing the quality of care is an important topic. Quality of care is a broad concept, and it encompasses various aspects of health care. Most commonly used is the Institute of Medicine's definition of quality of care, which distinguishes 6 different domains: safety, effectiveness, timeliness, patient centeredness, efficiency, and equity [1]. Patient safety refers to the notion that provided care should prevent patients from harm [1]. Effectiveness reflects the use of appropriate interventions and treatments [1]. Timeliness refers to delivering health care services on time [1]. Patient centeredness is about tailoring care to the unique patient's needs and preferences and engaging them and their proxies in decision-making [1,2]. Efficiency deals with how well resources are used and about avoiding waste [1]. Equity ensures everyone has equal access to the best possible care, independent of personal characteristics or geographic location [1]. Traditionally, quality of care has been approached from a professional's perspective, aiming to increase the likelihood of desired health outcomes. In 2015, the World Health Organization (WHO) reformulated the term patient centeredness into person centeredness, emphasizing that patients are more than just their health condition and proposing a broadened scope for health and well-being [3]. With this pivot shift from conventional biomedical health care models to a more holistic approach, patient experiences have become an important health care quality outcome, and patient-reported experiences have evolved into important indicators for quality of care [4,5].

Patient-accessible electronic health records (PAEHRs) are assumed to enhance the quality of care because they provide users with information about their health and health care [6-8]. Information can be provided in a one-way manner, by sharing health data in a patient portal or interactively when the system supports messaging between patient and care provider [9-12]. Either way, providing patients with their health data promotes empowerment and enhances people's engagement in their care plans [6,7,13]. Consequently, health consciousness (ie, the inclination to take health actions), therapy adherence, and self-management of health improve, all of which contribute to better health outcomes [8,9,13-16]. Moreover, transparency of PAEHRs is reported to enhance patient safety, for instance, because patients can identify errors in their health records and have them corrected [12,17,18].

PAEHRs in Adolescent Health Care

The growing body of literature reporting the effect of using PAEHRs on quality of care predominantly stems from adult health care. Research on the impact of using PAEHRs on the quality of care among children, adolescents, and their parents is limited because the development of PAEHRs for these target groups is delayed by age-specific challenges regarding autonomy and confidentiality [19,20]. Meeting these challenges during the development of PAEHRs is important because research shows that adolescents only share information with professionals who assure their confidentiality [21-23].

The protection of confidentiality and access to health information differs depending on the country or state. While there are different legal measures in place to safeguard confidentiality, all health care systems face the challenge of transferring access rights from parents to adolescents [20,24,25]. Initially, parents have the right to their child's health information, but as children grow into adolescence, and therefore in capacity and autonomy, these rights are transferred to the adolescent [26,27]. This transfer, varying across and within countries, can be gradual, with both parents and adolescents having access, or occur at a specific age [20,24,25]. Solutions for the emerging autonomy and confidentiality issues aim to balance adolescent autonomy and confidentiality with parental involvement [26-28]. In the United States, laws explicitly safeguard parents' rights to access their children's health information [25,29]. Contrastingly, countries such as Canada, the United Kingdom, the Netherlands, and most Scandinavian nations more strongly emphasize the rights of adolescents, depending on their capacity and maturity [24,30]. Restrictions on access to health information for both parents and adolescents vary globally, from shared access during a specified period to no access at all during adolescence [20,24]. The age at which adolescents can access their health information differs from any age in Finland and Estonia to 18 years in Austria and New Zealand [20,24]. Consent from either the adolescent or the parent may be necessary, with certain jurisdictions permitting adolescents to restrict parental access [20,25].

Objectives

In the Netherlands, a PAEHR named Iuvenelis has been developed for children, adolescents, and their parents. Iuvenelis is used in an interdisciplinary manner in preventive child health care and youth care. It is accessible to adolescents aged ≥ 12 years and to parents of children aged from 0 to 16 years. Investigating the impact of using Iuvenelis on perceived quality

of care among adolescents and parents will contribute to knowledge about using PAEHRs in an age group that is evolving toward autonomous adulthood. This study aimed to investigate how Dutch parents and adolescents visiting preventive health care and youth care perceived the impact of using a client-accessible interdisciplinary health record on quality of care, exploring both the experiences of active users and the expectations or first impressions of nonusers.

Methods

Research Design

A qualitative design with a phenomenological approach was chosen to explore how parents and adolescents perceived the impact of using Iuvenelis on the quality of care [31]. A total of 12 in-depth interviews with 1 to 3 people simultaneously were conducted between October 11 and November 25, 2021. We reported our qualitative study according to the COREQ (Consolidated Criteria for Reporting Qualitative Studies) [32]. [Multimedia Appendix 1](#) contains the completed COREQ checklist for this study.

Study Setting

The Dutch North Veluwe region consists of 6 municipalities. These municipalities commissioned 2 organizations providing preventive child health care to children aged 0 to 3 years and children aged 4 to 18 years and 1 organization providing youth care to integrate their services in the Centre for Youth and Family (CJG). The CJG is a network organization that houses professionals from the 3 parent organizations involved. Since 2015, the CJG has provided preventive health care to all 38,000 children aged from 0 to 18 years in the region and provided additional youth care for children and families with behavioral or sociopsychological problems [33]. Both preventive child health care and youth care refer to parents, children, and adolescents as clients rather than as patients. Using a participatory approach, the CJG in 2016 developed a quality standard for their services, following the European “Quality 4 Children” protocol [34]. In dialogue sessions with parents and adolescents, they jointly wrote a document that defined quality of care from a client’s perspective [35]. The document establishes 3 core values for quality—“child-centredness,” “partnership between family and professionals,” and “families in charge when decisions are made”—and describes the corresponding supportive professional behavior for each value [35]. Supporting the integration of services, the electronic health record “Iuvenelis” was built, to which all CJG professionals report. Furthermore, to support client autonomy and collaboration between professionals and families, Iuvenelis includes a tethered client portal in which parents and adolescents

can read everything professionals report, such as visit notes, measurements, test results, and referrals. They can manage appointments, send secure messages to professionals, ask questions, comment on written reports, and request corrections of errors. Compliant with Dutch legislation, adolescents receive automatic access to the portal at the age of 12 years [36]. At the same moment, the portal closes for parents, who have a legal right to access Iuvenelis until their child is 16 years of age. However, this right can only be effectuated when their child personally grants permission. When parents are granted access to their child’s record between 12 and 16 years of age, their child can still have single visit reports shielded from them. Iuvenelis was introduced in September 2019.

Study Population and Inclusion

The study included the parents of children aged 0 to 16 years and adolescents aged ≥ 12 years, living in the North Veluwe region, further referred to as clients. Clients who visited the CJG in September 2021 were invited personally by CJG professionals, and some general characteristics were reported, such as sex, age, educational level, and native country. Clients who expressed interest in participating were contacted by email or phone to explain the nature and purpose of the interview and to make an appointment. Where feasible, clients were invited to join focus group interviews at a CJG location. Those unable to attend a group session were offered an individual or dual interview live at the location of their choice or on the web. Purposive sampling ensured a varied group representing both sexes, parents and adolescents, various educational levels, active users of Iuvenelis and nonusers, both visitors of preventive health care and youth care, and inhabitants from all participating municipalities. We included parents from native Dutch and migratory backgrounds. In this paper, we use the term migratory background for immigrants who moved to the Netherlands, regardless of their command of the Dutch language. In total, 12 interviews were conducted with 20 participants. Apart from 7 (58%) individual interviews, 2 (17%) double and 3 (25%) triple interviews were conducted. Except for 1 (8%) triple interview with a mother and her 2 teenage children, group interviews consisted of only parents or only adolescents, and respondents did not know each other.

Data Collection

To create an interview topic guide ([Multimedia Appendix 2](#)), a working session was convened with an interdisciplinary expert panel of 8 professionals. On the basis of the CJG quality standard and the overarching Institute of Medicine framework [1], they explored what aspects of client-perceived quality of care could be influenced by using Iuvenelis. [Textbox 1](#) presents the main topics from the semistructured interview guide.

Textbox 1. Client interview main topics, with sample questions from the interview guide.

General

- Are participants acquainted with Iuvenelis?
- How have their experiences been in general?
- If they were not acquainted, what are their first impressions?

Safety

- How do participants feel about security of their data?
- How do participants feel about detecting errors?
- How do participants value the view log?

Effectiveness

- How do participants experience completeness and understandability of reports in Iuvenelis?
- How do participants value professional expertise?

Timeliness

- How do participants experience the possibility of 24/7 access to their health data?
- How do participants experience the possibility to manage their own appointments?
- How do participants experience the possibility to ask questions at their convenience?

Person centeredness

- To what extent do participants perceive an influence of using Iuvenelis on client-professional collaboration or communication?
- To what extent do participants perceive an influence of using Iuvenelis on equal relationship?
- To what extent do participants perceive an influence of using Iuvenelis on sense of ownership?

Efficiency

- How do participants experience collaboration between disciplines through Iuvenelis?
- How do participants experience the use of interdisciplinary shared care plans?

Equity

- How do participants experience ease of access and ease of use?
- How do participants experience comprehensibility of record content?
- Were participants informed about the existence of Iuvenelis?

All participants were interviewed once by an experienced female interviewer (JB). For the first 6 of the 12 (50%) interviews, a female research assistant (CA_dM) assisted as an observer and note-taker. Individual interviews lasted 30 to 60 minutes, and double and triple interviews lasted 90 minutes. When the participants were not acquainted with the client portal, the first part of the interview was used to demonstrate its functionalities in real time, followed by the main interview, which then focused on expectations and first impressions instead of experiences. Every interview was audio recorded, supplemented by note-taking, and by video recorded for web-based interviews.

Data Analysis

The interviewers transcribed all interviews verbatim for analysis. A member check was conducted with all participants to affirm transcript accuracy. Data were analyzed in ATLAS.ti (version 9; ATLAS.ti Scientific Software Development GmbH). On the basis of the topic list with the 6 domains of quality of care as a

framework, a preliminary codebook was written. In accordance with best practices, data collection and analysis were conducted in an iterative, cyclical process, checking for data saturation. The interviewing authors (JB and CA_dM) conducted a thematic analysis, rereading and coding all transcripts independently [37,38]. After coding a full transcript, the 2 researchers discussed discrepancies in coding until consensus was reached. Simultaneously, in a continuous process, additional codes were added to the codebook, coding definitions were refined, and transcripts were recoded when necessary. Saturation was discussed during analysis and was reached after 12 interviews. Subsequently, JB and CA_dM grouped all codes into major themes and discussed the interpretation of themes with all authors.

Research Team and Reflexivity

The interviews were conducted by a researcher working as a policy advisor at the CJG and a research assistant, both trained

in qualitative research. Although 1 interviewer worked in the CJG, no working relationship had been established with any of the participants before the study. Every interview started with an introduction of the interviewers and an explanation of the study goal. Combining an experienced researcher with inside knowledge of the CJG and Iuvenelis (JB) with a young researcher from outside the CJG (CAAdM) had 2 advantages: first, when present during the interviews with adolescents, the younger researcher could identify easily with the participants and vice versa; second, during analysis, comparing observations and discussing interpretations from both inside and outside perspectives enriched the process of interpretation and limited the risk of bias.

Ethical Considerations

The study was carried out following relevant guidelines and regulations, complying with the Netherlands Code of Conduct for Scientific Practice. On these grounds, the research protocol was approved by the Social Sciences Ethics Committee of Wageningen University (2018-24-Benjamins). All participants received an invitation beforehand with information about the study and gave explicit verbal consent at the beginning of the interview. Each interview was recorded and transcribed verbatim, including verbal consent.

Results

General Characteristics

Of the 20 participants, 13 (65%) parents and 7 (35%) adolescents were interviewed individually (n=7, 35%), in pairs (n=4, 20%) or in triplets (n=9, 45%). Initially, 23 participants were included, of whom 3 (13%) dropped out due to agenda mismatches. The participants represented both sexes, parents, and adolescents from different educational levels, from native Dutch and migratory backgrounds, and from all involved municipalities and also represented those making use of preventive child health care and youth care services. All adolescents were making use of youth care services. (Table 1).

A total of 35% (7/20) of the participants were not acquainted with the client portal before the interview, and 85% (6/7) of them were from a migratory background. Of the participants who were acquainted with the client portal, 46% (6/13) had received information from a CJG professional and, 54% (7/13) had discovered the portal through a questionnaire about Iuvenelis. In total, 30% (6/20) of the participants came to the CJG office, 50% (10/20) of them were interviewed in their own homes, and 20% (4/20) of the participants had web-based interviews.

Table 1. Characteristics of participants in the client interviews.

	Parents (n=13), n (%)	Adolescents (n=7), n (%)	Total (N=20), n (%)
Sex			
Male	2 (15)	2 (29)	4 (20)
Female	11 (85)	5 (71)	16 (80)
Educational level			
High	3 (23)	2 (29)	5 (25)
Middle	4 (31)	3 (43)	7 (35)
Low	6 (46)	2 (29)	8 (40)
Native country			
Netherlands	6 (46)	7 (100)	13 (65)
Kosovo	1 (8)	0 (0)	1 (5)
Syria	1 (8)	0 (0)	1 (5)
Afghanistan	2 (15)	0 (0)	2 (10)
Thailand	2 (15)	0 (0)	2 (10)
Sudan	1 (8)	0 (0)	1 (5)
Municipality			
Oldebroek	1 (8)	1 (14)	2 (10)
Elburg	1 (8)	0 (0)	1 (5)
Nunspeet	2 (15)	1 (14)	3 (15)
Harderwijk	5 (38)	3 (43)	8 (40)
Ermelo	3 (23)	2 (29)	5 (25)
Putten	1 (8)	0 (0)	1 (5)
Visiting preventive child health care or youth care			
Preventive child health care	10 (77)	0 (0)	10 (50)
Youth care	3 (23)	7 (100)	10 (50)
Acquainted with the portal			
Yes	6 (46)	7 (100)	13 (65)
No	7 (54)	0 (0)	7 (35)

Interview Outcomes

A code tree ([Multimedia Appendix 3](#)) was created with branches for all 6 aspects of quality of care: safety, effectiveness, timeliness, person centeredness, efficiency, and equity [1]. One additional theme emerged, related to professional attitude and behavior. Because this theme is linked with person centeredness, we divided the theme of person centeredness into 2 subthemes: client perspective and professional attitude. Most expressions from the participants could be coded in the domain of person centeredness (668/1749, 38.19%), followed by safety (382/1749, 21.84%), equity (337/1749, 19.27%), timeliness (158/1749, 9.03%), and efficiency (135/1749, 7.72%), whereas effectiveness was mentioned the least (69/1749, 3.95%). When experiences across quality-of-care domains were compared, it appeared that positive experiences were expressed for person centeredness, safety, and timeliness, whereas the domains equity and effectiveness evoked predominantly expressions of concerns. The participants expressed mixed feelings about the domain

efficiency. In the following paragraph, more in-depth analyses of the participants' reflections on individual dimensions of quality of care will be presented, starting with the domain that generated the highest number of codes.

Person Centeredness

Subtheme A: Client Perspective

Both parents and adolescents reported that rereading information in the client portal contributed to person centeredness because it helped them to *recollect* what had been discussed during a visit, to *get an overview* over a longer period, and to *prepare* for the next visit:

Sometimes it is so crowded in my head. Then I start thinking: what was it all about? [Mother, 2 children, respondent 7.2]

It's more like when I am struggling with something that we have discussed earlier that I think: Hey, wait a minute. Didn't we already talk about this once?

And I can reread our conversation. [Female adolescent, aged 17 years, respondent 10]

Using the client portal to get an overview was even more important for the parents with a migratory background, although only 1 of them had been using the portal before the interview. However, after watching the portal demonstration and accessing their own child's health record, all parents from a migratory background considered access to the client portal to be very valuable. They expected that both rereading and reading with others would be vital. Rereading, and using a web-based translation tool when they did not comprehend the Dutch text, would help them to get a *better understanding* of what was discussed during a previous visit. A total of 50% (3/6) of the mothers with a migratory background had partners who understood Dutch better than they did. Rereading together after a mother's visit to the CJG would *provide* the father with all relevant *information* and would help the mother *recollect* what was discussed or provide her with information that she had not grasped yet during the visit:

This one (client portal), this is good! My husband always asks: "How big was his head, how tall was he and how many kilos." And then I go: "Oh my goodness, I forgot! Do I need to memorize that?" Now I can say: "Hey, you can log in and see for yourself what has happened." [Mother, 1 child, respondent 2.1]

Involving relatives in one's care was an aspect of person centeredness that not only the parents with a migratory background reported as a benefit from access to the client portal. Most parents valued that a partner who had not been present at the physician's visit could read the notes afterward. For adolescents, it felt easier to have parents read a visit report than to recall the whole conversation themselves, although they also valued the possibility of actively withholding information from their parents if they wanted to. Finally, rereading with relatives or friends was reported as helpful as well, when *preparing* for a next visit, or when *decisions* had to be made about the care process:

I have a Syrian friend who does not speak Dutch. Her daughter has a growth problem. I helped her and we took the information from the growth chart in this portal, bringing it with us to the hospital. [Mother, 3 children, respondent 11]

Being able to reread information, the parents and the adolescents felt *well informed* and *engaged* in their care plan. They also valued being part of the reporting process, discussing beforehand what should be reported and how. The combination of reporting together and rereading information enhanced their sense of *ownership* and contributed to *equal client-professional collaboration*:

Now I know, because I can check myself, when my children need vaccinations [Father, 5 children, respondent 3.2]

You construct the report together, so to speak, and you can both navigate the plan a little. [Mother, 2 children, respondent 7.3]

Both parents and adolescents would like to have *more ownership* than was facilitated by the client portal. Some parents expressed the need to *add* more *information* to Iuvenelis to create a full overview of all health and welfare issues concerning their child. Adolescents wanted to be more in control of who accessed their health records; they wanted to *actively give access* to professionals or at least be able to see beforehand who had access to their record instead of reading afterward in their view log who had accessed their health information:

At least I want to see beforehand which professional is authorized to access my health record, instead of seeing who has accessed my record afterwards. [Male adolescent, aged 17 years, respondent 5.1]

Subtheme B: Professional Attitude

Numerous participants emphasized that a *professional attitude* was an important underlying condition to deliver person-centered care and to experience the possible benefits of using Iuvenelis. The transparency of Iuvenelis contributed to a sense of *trust*, but only if professionals reported respectfully, showing that they did take clients seriously. Being able to see in a view log who accessed your health record was considered reassuring and enhanced trust. A mother stated the following:

You should consider very carefully how you report, because you are inviting me: "Go ahead, read it." You are giving full access to the health record. [Mother, 2 children, respondent 7.3]

On the other hand, trust could be damaged if professionals did not report respectfully or did not respect a client's privacy. After experiencing numerous instances where professionals were speaking about her, 1 parent chose not to access the client portal, to protect herself from losing trust in her current care provider:

I have decided that I trust "X" completely. Why should I read my health record when I do not need to and take the risk to read something that might harm that trust? [Mother, 2 children, Respondent 9]

Safety

Both parents and adolescents were satisfied with the *security* of their *health data* and the way professional authorization was organized. They generally valued the possibility to see in their view log who accessed their health record. Adolescents all valued their *right to decide* about access for their parents. Knowing how safety was warranted was an important factor contributing to their *trust* in the system:

This afternoon I saw that someone had accessed my daughter's record. But I remembered I approved that person. It's nice to know that my approval is needed beforehand. [Mother, 4 children, respondent 7.1]

I had problems with my parents, and I don't know if that's still in all those documents. Then it is nice indeed that you can decide, what they can and can't see. [Male adolescent, 17 years, respondent 5.1]

However, half of the portal-using participants were well informed about the privacy and data security measures, and knew where to find the view log. For 1 adolescent, the view log

was a reminder that professionals were discussing her situation without her being present, which she did not appreciate:

Although I like seeing who has accessed my health information, it also gives me stress. Because once they discussed my condition in a meeting with several people and I was not there. They were talking about me without me, so to speak, and that's not okay. When I check the view log that situation comes back in mind. [Female adolescent, aged 18 years, respondent 5.2]

Can other people [outside the CJG] see my child's record? How do I know that you don't give it to other people? Because everything is web-based. [Mother, 1 child, respondent 2.1]

Correcting errors is generally considered a part of the element "safety" [12]. Throughout the interviews, 2 adolescents and 3 parents encountered registration errors or missed appointments without follow-up when checking their portal. They said identifying errors did not upset them. Quite the reverse; they appreciated the possibility to detect errors, report them, and have them corrected. Moreover, being able to correct mistakes increased their sense of ownership over their care process. The parents said it was important to correct found errors, whereas adolescents said they would not ask for correction:

Sometimes things go wrong. For example, E had missed a vaccination. So now we can check the record ourselves and see which vaccination he needs. [Father, 5 children, respondent 3.2]

Equity

Independent of their native country and educational level, participants thought very positively of the client portal's usability. The portal was experienced as easy-to-use and intuitive. The parents and the adolescents could log on to the system easily using digital ID, because people had familiarized themselves with this verification procedure during the COVID-19 pandemic. Usability on mobile phones was also considered good:

Logging in with DigiD makes things easier actually, solving the whole hassle of passwords. [Mother, 4 children, respondent 7.1]

For me, it must be well-organised and then it's good. The way it is constructed right now, it's clear, uncluttered and you can read everything. I think I will look more often. [Mother, 2 children, respondent 7.3]

The parents and the adolescents also considered most recorded content *comprehensible*. However, some portal features, for example, vaccination overview and planning appointments, required explanation, and the parents and the adolescents sometimes encountered jargon or incomprehensible abbreviations:

I understood most things I read. But I thought about some information from when I was a little kid, some expressions: that must be only for doctors. [Female adolescent, aged 18 years, respondent 12]

The most serious concern expressed by parents was that not all clients were informed *equally* about the existence of Iuvenelis. A total of 7 (35%) out of 20 participants had not received any information about Iuvenelis before the interview, and 86% (6/7) of them were from a migratory background. One parent from a migratory background did use the client portal to manage appointments but was not aware that she could also reread visit reports:

If I had not been here, I would not have known anything about it at all, and that's a shame. [Mother, 1 child, respondent 2.3]

The parents presented many options for improving communication. Emphasizing the importance of providing more equal information to all population groups, 1 parent offered to participate in information meetings with mothers from migratory backgrounds:

Some mothers (with a migratory background) are unsure about their language proficiency. For them, it is easier to do it through the internet. [Mother, 3 children, respondent 11]

Timeliness

The client portal's 24/7 accessibility did not contribute to *faster* access to care. However, it did provide parents and adolescents with the opportunity to ask questions or schedule appointments easily and at their *convenience*. Especially, parents valued this opportunity as *time saving*, including the immediate access to their health information without the interference of a CJG professional:

Suppose I get very anxious during the weekend about certain behaviour I observed. I would prefer to search for information right then and there, instead of sending an email and waiting several days until someone responds. I think it's a plus that I can check the client portal and ask my questions immediately. [Mother, 2 children, Respondent 7.3]

I rescheduled my appointment once through the portal. Very convenient and timesaving! [Mother, 2 children, respondent 7.2]

Efficiency

In Iuvenelis, all CJG professionals had access to all relevant information stored in the same place, which was considered an advantage contributing to efficiency. Consequently, the parents and the adolescents did not have to repeat their stories when visiting a new professional in the CJG:

I think it is very convenient when you visit several people in the same period that all information is in one place. So, they can make use of each other's information. [Female adolescent, 15 years, respondent 6]

However, both parents and adolescents saw room for improvement in expanding Iuvenelis toward other care providers and in a more active role for themselves in uploading information from other care providers in their client portal. They felt that if all their health data were stored in one place and accessible to all their care providers, it would be easier for both

care providers and clients themselves to create a clear overview and manage their care:

I hope lines between all professionals will be shorter. Eventually, I hope my children will have all their health data in this record, that this will be their complete and only health record. [Mother, 2 children, respondent 8.3]

Effectiveness

Parents and adolescents did not associate using Iuvenelis with effectiveness. Although a fully accessible health record allows clients to engage in the management of their care process, none of the participants commented on the actual care process and whether the right choices had been made.

Parents and adolescents did comment on the process and quality of reporting: they felt that reporting quality could be improved. Some reports contained mistakes, and some were incomplete or missing. One parent expressed the concern that reports were sometimes prejudiced, elaborating on risk factors and neglecting protective factors:

They only report what is wrong. Do you know what could really help? If you would read in your child's record what is going well if someone would write down what a lovely little boy he is. [Mother, 2 children, respondent 9]

Discussion

Principal Findings

With this study, we explored how parents and adolescents visiting preventive health care and social care perceived the quality of care when using Iuvenelis. Both the experiences of active users and the expectations or first impressions of nonusers were included. The results suggest that using Iuvenelis contributed to some, but not all, aspects of quality of care. On the positive side, parents and adolescents felt better informed and expressed more engagement in the care process than before introduction of Iuvenelis. They felt more in control of their health data, reported having faster and simpler access to their health information, and found it easier to manage appointments or ask questions at their convenience. Portal usability and data safety were regarded as high, and interdisciplinary collaboration in Iuvenelis was considered to enhance efficiency. The parents from a migratory background expected that portal access would give them a better understanding of and more control over their care processes.

However, parents expressed concerns about possible unequal access due to a lack of information for the parents from a migratory background. Furthermore, both parents and adolescents saw room for improvement in the broader interdisciplinary use of Iuvenelis. Finally, they felt that effectiveness could be improved by more complete reporting regarding protective factors as well as risk factors.

Comparison With Prior Work

Overall Contribution to Quality of Care

Previous research investigating quality of care in relation to using PAEHRs predominantly focused on adult health care. These studies reported largely the same outcomes as our study, although described from a care provider's perspective. Using a PAEHR was reported to contribute to person centeredness [7,39,40], safety, and efficiency [16,39,40]. Contrary to this study, prior studies also show a positive impact of using a PAEHR on effectiveness [16,39,40]. Some studies report that patient portals enhance timeliness through messaging functionalities or quicker access to results [41-45].

Person Centeredness and Professional Perspective

Some participants emphasized the importance of a person-centered professional attitude, which they considered fundamental for Iuvenelis' contribution to quality of care. When professionals reported respectfully in Iuvenelis, this enhanced the client's trust in their care providers, whereas earlier experiences with professionals not respecting a client's privacy damaged that trust. An extensive review by Scholl et al [46] generated a patient-centered care model that places a professional's attitude central in the delivery of person-centered care. In this model, delivering patient-centered care relies on professionals embracing a person-centered attitude characterized by respecting a patient's unique preferences and needs, building a professional-patient relationship based on equality, and viewing a patient's health from a biopsychosocial perspective [46]. Leeuwis and Aarts [47] stated that complex interventions, such as technological innovations, usually require change on different levels. These changes, on a technological, organizational, and professional level, are considered interdependent [47]. In this case, implementing a PAEHR to enhance person centeredness is not only about introducing the technological tool; the implementation needs to address professional attitude and behavior as well. In turn, changes in professional behavior and attitude require adjustments at the organizational or institutional level. These interdependencies should be anticipated when organizations start implementing a PAEHR, and the necessary changes on an organizational and professional level should be planned and facilitated in addition to the development and implementation of the tool itself.

Equity

Equity emerged in this study as an issue of concern because most participants with a migratory background appeared to be unaware of the existence of a client portal, as opposed to 1 participant with a native background. Diving a bit deeper into this, anecdotal evidence may suggest that professionals hesitated to inform clients about the existence of the client portal when they noticed that a client's knowledge of Dutch was limited. Unawareness of the existence of a patient portal has been reported as a main barrier for using a patient portal [48,49] and could be resolved by provider encouragement, which is an important contributor to portal use [50-52]. However, when providers selectively encourage certain groups of people to use a patient portal and neglect others, they could enhance disparity. Previous research shows that persons living in vulnerable

circumstances, such as lower-educated people or persons from a migratory background, make less use of patient portals than average [17,42,53-58]. The literature on the digital divide reports that social exclusion can lead to digital exclusion and that the introduction of new technology then might unintentionally reinforce already existing health disparities [59-61]. In total, 2 studies investigating a provider's role in patient portal use reported that professionals play a role in this reinforcement: higher-educated and White patients were more likely to report being encouraged by health care providers to use a client portal than lower-educated patients and patients from migratory backgrounds [50,51]. Antonio et al [62] stated in a review that "healthcare providers' prejudgments may further exclude populations that are already underserved."

This is an important issue to address because research shows that people, especially those living in vulnerable circumstances, experience benefits from using a PAEHR [42,43,63,64]. In our study, parents from migratory backgrounds reported that rereading their health information and sharing it with family members or friends would provide them with a better understanding of the care process and would increase their engagement in care. We concluded that ensuring that all clients are equally informed about the existence of a client portal is not only necessary to prevent further disparities but could even diminish existing disparities [65]. This may require adapted measures for specific population groups, for example, using informal meetings with the parents from migrant backgrounds to inform them in their language about Iuvenelis. In addition, professionals need to be made aware of the risk of the digital divide and of their crucial role in conquering this phenomenon.

Confidentiality

On the basis of the known bottlenecks to developing PAEHRs for adolescents [26,27], we expected data safety, confidentiality, and privacy to be an issue of concern for at least some of our participants. However, surprisingly, participants did not express concerns about their data safety. Adolescents did value highly how their confidentiality was protected and reported that this contributed to their trust in their care provider. Comparably, recent studies investigating adolescent use of PAEHRs suggest that adolescents are not concerned about their confidentiality when using a PAEHR [8,13,18,23]. A recent review investigated the experiences of parents and adolescents using a PAEHR in hospital, primary, and mental health care settings versus the expectations of parents and adolescents without access to a PAEHR. In this review, the authors found that parents and adolescents without access to a PAEHR anticipated confidentiality issues when using a PAEHR, whereas parents and adolescents using a PAEHR did not experience these issues [66]. In a similar vein, research that compared professionals' general concerns about using PAEHRs beforehand with experiences after a period of using a PAEHR shows that anticipated worries were not always justified. For example, an expected increase in workload and excessively anxious patients did not occur after introducing PAEHRs [67-69]. Confidentiality issues could have been one of the expected problems that did not evolve. Another explanation of the contrast between expected bottlenecks and real experiences may be that the explicit focus in the literature on confidentiality issues has

initiated specific awareness for this topic during the development of Iuvenelis and has led to the implementation of successful solutions.

Integrated Care

The participants considered the interdisciplinary use of Iuvenelis a contribution to efficiency and even expressed a need to expand the use of Iuvenelis to other disciplines outside the CJG. This would allow them to view all their health data in one place. Parents and adolescents stated that, in their opinion, this would contribute to efficiency. However, with their remarks, participants draw upon an additional aspect of quality of care, integrated care, that the WHO has added recently [1,70]. The WHO defines integrated care as "providing care that is coordinated across levels and providers and makes available the full range of health services throughout the life course." The parents and the adolescents even challenged the CJG organizations to extend opportunities for interdisciplinary collaboration within Iuvenelis, facilitating them to gather all their health information here. With that challenge, the parents and the adolescents confirmed the value of the Dutch aim for integrated care in child health care and youth care [71]. This aim is also reflected in the recently established Healthy and Active Living Agreement between the Dutch government, municipalities, and public health associations [72], although it is not yet common practice throughout the country.

Differences Between Parents' and Adolescents' Experiences

Although parents' and adolescents' perceptions were similar in many aspects, differences were reported as well. Parents considered it more important to correct errors than adolescents and valued the web-based option to ask questions and manage appointments more highly than adolescents. Comparably, recent studies among adolescent patients show that adolescents are less likely to speak up about mistakes in their records than their parents [73,74], and are more reluctant to send direct messages in the PAEHR to their caregivers than adults [13,23]. Both parents and adolescents liked to share record content with their close ones, but adolescents also valued the opportunity to shield specific content from their parents when needed. Adolescents considered deciding who had access to their health information vital to exercising ownership over their health information. In line with this, a recent review reports that teens believe they should have control over what remains confidential in their medical records and what their parents can access through proxy portal accounts [23].

Strengths and Limitations

Recruiting a well-balanced group of participants in this qualitative study was a strength of this study, compared to our previous studies on Iuvenelis, where adolescents were represented in small numbers and participants with migratory backgrounds could not be included [75,76]. The inclusion of the most important characteristics in this study enabled us to explore different client perspectives. Choosing a qualitative research design made it possible to collect rich, in-depth information about the client's expectations of and actual experiences with using Iuvenelis.

Due to the COVID-19 pandemic, organizing focus groups proved to be difficult. Although some triple interviews could be organized, most participants were interviewed individually or in couples. Consequently, our study lacked some of the interaction that is usually generated in larger groups, which could be considered a limitation [77]. We partly managed to overcome this limitation because we collected and analyzed data in a continuously iterative process. This meant that topics that were brought up in the first interview could be explored further in the following interviews.

As JB had a role as a policy advisor in the CJG, she was able to introduce the participants to Iuvenelis who were not yet acquainted with the client portal, which allowed us to include more parents with a migratory background and to add valuable information to our data. However, combining a portal demonstration with an interview about how clients perceived the quality of care using this portal might have created a respondent bias: the interviewer's positive attitude toward the client portal could have evoked socially desirable answers. To enhance trustworthiness, the interviewers followed the interview guide as closely as possible, allowing some adaptation to the conversational flow. A member check was conducted, transcripts

were coanalyzed with a researcher with no connections with Iuvenelis or the CJG, and reporting followed the COREQ checklist [32,78].

Conclusions

Using Iuvenelis is expected to contribute to experienced quality of care from the perspectives of both parents and adolescents, specifically to the aspects of person centeredness, timeliness, and safety. Parents and adolescents feel better informed, experience a greater sense of ownership, and are satisfied with data security and portal usability. Clients also report that using Iuvenelis contributes to integrated care. Some quality aspects, however, such as equity in portal access, still need addressing. In general, client information about the portal needs to be improved, specifically focusing on people in vulnerable circumstances, such as those from migratory backgrounds. In addition, to maximize the potential benefit of using Iuvenelis, stimulating a person-centered attitude among professionals is important. With our study, we have investigated parents' and adolescents' perspectives regarding all domains of quality of care. However, considering the small number of adolescent participants, adding quantitative data from a structured survey could strengthen the available evidence.

Data Availability

As interview transcripts contain sensitive information, these will not be published in a separate data set.

Authors' Contributions

JB, EdV, and AH-N conceived and designed the study. JB and CAdM collected and analyzed the data. JB drafted the manuscript as first author. All authors provided critical feedback, helped shape the analysis and manuscript, and have read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Completed COREQ (Consolidated Criteria for Reporting Qualitative Studies) checklist.

[[DOCX File , 29 KB - jopm_v16i1e50092_app1.docx](#)]

Multimedia Appendix 2

Interview topic list.

[[DOCX File , 18 KB - jopm_v16i1e50092_app2.docx](#)]

Multimedia Appendix 3

Codetree, displaying all applied codes, grouped in colours around every single aspect of quality of care.

[[PDF File \(Adobe PDF File\), 652 KB - jopm_v16i1e50092_app3.pdf](#)]

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Abbreviations

CJG: Centre for Youth and Family

COREQ: Consolidated Criteria for Reporting Qualitative Studies

PAEHR: patient-accessible electronic health record

WHO: World Health Organization

Edited by S Woods; submitted 10.07.23; peer-reviewed by J Hagström, Y Chu; comments to author 30.08.23; revised version received 11.12.23; accepted 20.03.24; published 23.04.24.

Please cite as:

Benjamins J, de Vet E, de Mortier CA, Haveman-Nies A

The Effect of Using a Client-Accessible Health Record on Perceived Quality of Care: Interview Study Among Parents and Adolescents
J Particip Med 2024;16:e50092

URL: <https://jopm.jmir.org/2024/1/e50092>

doi: [10.2196/50092](https://doi.org/10.2196/50092)

PMID: [38652532](https://pubmed.ncbi.nlm.nih.gov/38652532/)

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Original Paper

Getting to Know Your Patient: Content Analysis of Patients' Answers to a Questionnaire for Promoting Person-Centered Care

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Abstract

Background: Person-centered care (PCC) encourages patients to actively participate in health care, thus facilitating care that fits the life of the patient. Therefore, health care professionals (HCPs) need to know the patient. As part of a broad policy for improving PCC, a digital questionnaire (“We would like to know you”) consisting of 5 questions has previously been developed to help HCPs to get to know the patient with the help of patient and staff involvement.

Objective: The purpose of this study was to provide insight into the content and aims of the questionnaire to understand its potential and usability.

Methods: We conducted a qualitative, retrospective content analysis of patients' answers using NVivo Pro (QSR International). The questionnaire was used in the outpatient neuro-oncology department of a Dutch academic hospital.

Results: Of 374 invited patients, 78 (20.9%) completed the questionnaire. We selected a sample of 42 (54%) of the 78 patients. Patients used a median of 16 (IQR 7-27) words per question, and most answers were easily interpretable. When asked about important activities, social activities, sports, or maintaining a normal life were most frequently mentioned. Patients wrote about fear of the disease, its possible influence on life, or fear of the future in general. Patients wanted HCPs to know about their care and communication preferences or shared personal information. They formulated expectations about effective treatment, communication, and the care process.

Conclusions: The questionnaire seems usable because patients provide interpretable answers that take little time to read, which HCPs can use to personalize care. Our study shows the potential of the questionnaire to help deliver PCC.

(*J Particip Med* 2024;16:e48573) doi:[10.2196/48573](https://doi.org/10.2196/48573)

KEYWORDS

person-centered care; shared decision-making; patient engagement; positive health

Introduction

Background

Person-centered care (PCC) is a model of care in which the active participation of patients in their own health care is encouraged. PCC is about providing holistic care to patients and not only about focusing on the patient's disease to facilitate

high-quality health care. A holistic view, taking the socioeconomic environment and psychological status into consideration, is important to obtain an overall understanding of the patient's illness and is necessary for high-quality care [1].

Several definitions of PCC have been presented in the literature. Morgan and Yoder [2] defined PCC as follows: “PCC is a holistic (bio-psychosocial-spiritual) approach to delivering care

that is respectful and individualized, allowing negotiation of care, and offering choice through a therapeutic relationship where persons are empowered to be involved in health decisions at whatever level is desired by that individual who is receiving the care.” Street [3] defines PCC using the combination of four domains: “(1) biopsychosocial approach to medical care, (2) patient as person/sharing power and responsibilities, (3) therapeutic alliance, and (4) coordinated care.” Listening to patients’ needs, values, and important topics is essential in health care. In the oath that new physicians take, they pledge to acknowledge patients’ values and needs and, in the Dutch oath especially, to listen to their patients [4,5].

Therefore, it is essential for a health care professional (HCP) to get to know the patient and to enhance communication with the patient to improve the mutual understanding of health care options and preferences. The acknowledged communication model to incorporate patients’ perspectives is shared decision-making (SDM). However, using SDM does not always mean that care is person centered. Generally, in SDM, discussing the patients’ preferences occurs after the HCP explains the available options and discusses the pros and cons [6]. SDM can result in a conversation where the HCP simply offers information and choices and cannot see the available options from the patient’s perspective [7]. Previously conducted studies have shown that health care interventions based on the patient narrative and getting to know the patient can be used to stimulate PCC in health care [8-10]. In addition, we have reason to believe that it is important to start the medical encounter by identifying what matters to the patient [11], so that the patient and the HCP together can decide which option is best in the patient’s context [7,12,13]. Barry and Edgman-Levitan [12] state that it is about teaching HCPs how to be effective partners in care. They specifically mention the potential of health care technologies that focus on better understanding patients’ experiences and eliciting patients’ needs and preferences.

In a large, Dutch academic hospital, as part of standard care in neuro-oncology, a technological initiative was introduced to facilitate PCC in daily health care. On the basis of the needs and preferences of stakeholders, patients, and HCPs of the hospital, a new, digital patient questionnaire “We would like to know you” was implemented, consisting of 5 questions. The aim of this initiative was to gather the health care preferences and needs of patients in a manner that would enable HCPs to seamlessly incorporate these needs and perspectives into medical consultations. It also aimed to provide patients the opportunity to express what they considered important for them. The initiative focused on enabling HCPs to use this information to make the consultation more receptive to patients’ contexts, needs, and preferences. [Multimedia Appendix 1](#) shows the format of the questionnaire administered to the patients.

Objective

An evaluation is needed to obtain information about the usefulness of this PCC tool in health care. Insight into the content of the patients’ written answers and its possible relevance for getting to know the patient is currently lacking. It is unknown whether respondents are able to answer the questions and whether these answers are interpretable. This

study filled this knowledge gap by evaluating patients’ answers to the questionnaire “We would like to know you.”

Methods

We conducted a retrospective content analysis using a qualitative, narrative research method to explore in depth the content of the questionnaire “We would like to know you” (hereafter, referred to as “the questionnaire”).

Context

The questionnaire was developed at a large university medical center in the Netherlands. It was introduced in December 2020 as part of standard care in the outpatient neuro-oncology clinic. This department specializes in oncological diagnostics and treatment of the central nervous system.

The questionnaire was developed before commencing this study as part of a broad policy of the academic hospital to improve and facilitate PCC in daily health care practice. An internal assessment was conducted using personal interviews and a patient participation network meeting from December 2020 to April 2021. The personal interviews focused on what patients thought was important personal information to share with their HCPs. They were also asked how they wanted to share this information. HCPs answered questions about how they wanted to receive patient narratives. Overall, 21 individuals were interviewed: 10 (48%) patients and 11 (52%) HCPs. The questionnaire was further developed at a network meeting for patient participation. At this meeting, 22 members were present: 6 (27%) patients; 10 (45%) hospital employees, including HCPs; 4 (18%) students; and 2 (9%) members of the hospital’s client council. In addition, input from a neuro-oncology patient panel (n=10) was collected. Overall, 7 (70%) patients, 2 (20%) HCPs, and 1 (10%) researcher were present. All members of this panel were patients currently in treatment at that time or patients who had been treated for a neuro-oncological disease. A selection of 4 possible PCC interventions was discussed. The group decided to use the questionnaire and further discussed whether the topics of the questions and the additional information buttons were suitable for the context of the neuro-oncology.

This input was used to develop the questionnaire. No alterations to the questions were made based on the discussion.

The Research Instrument

In this study, the questionnaire was further developed in the neuro-oncology patient panel (n=11). Overall, 8 (73%) patients or former patients, 2 (18%) HCPs, and 1 (9%) researcher participated. Again, the content of the questions and the information buttons were discussed. In addition, the format was further discussed. No alterations regarding the questions and information buttons were made. During the meeting, special attention was given to optimize the questionnaire so that it could easily be used by the patients in the clinical context and was embedded in the existing health care pathway.

This study’s questionnaire consists of 5 questions and an information button for each question. These information buttons were added to help patients answer the questions when they

needed guidance. The 5 questions of the questionnaire and the content of the information buttons are presented in [Table 1](#).

Table 1. Questions of the “We would like to know you” questionnaire.

Questions	Information buttons
1—What are important activities, now or in the future?	You can think of work, hobbies, or other ways you like to spend your time (traveling, sports, family and friends).
2—Which people are important in your life, and why are they important?	You can think of your partner, children, family, neighbors, friends, or people from your community, health care center, city, or other organizations.
3—What are you worried about concerning your health?	You can think of symptoms, fatigue, fear of pain, or concerns about specific things you might not be able to do in the future.
4—What do you think is important that your health care professionals know about you?	You can think of everything in relation to your care or treatment, like: do you want your doctor to address you with sir/madam or do you prefer an informal way of communication? Do you want your doctor to show pictures to explain something? Do you always want to bring a certain person to the consultation?
5—What do you expect from your treatment at the [large academic hospital]?	You can think of the results of your treatment, a regular contact person that you can always call or ask a question via e-consultations or anything else.

An internal assessment was conducted between December 2020 and April 2021. Overall, 2 HCPs of the neuro-oncology ward personally selected patients for the questionnaire based on the presumed diagnosis of a primary brain tumor and similarity of health care pathways, which included consultations with a nurse specialist, a neuro-oncologist, and a neurosurgeon. Selected patients received an invitation to answer the questionnaire together with a general introduction e-mail from the outpatient clinic before their first appointment at the hospital. From May 2021, patients were automatically selected through an electronic health record labeling system (diagnosis-treatment combination) that used the label of primary brain tumors.

The selected patients received an invitation through the hospital’s electronic personal patient portal. Patients could answer the questions on a voluntary basis, either individually or with the help of relatives, before the first hospital visit and during the entire treatment process. It was possible to answer the questions multiple times. After submission of the patient’s answers, the content of the questionnaire was accessible to HCPs involved in the patient’s care through the personal electronic health record. During internal staff meetings, the HCPs were instructed to read the patients’ answers before the consultation and were expected to address the relevant topics derived from the patients’ answers during the consultation.

Data Collection

The data consisted of patients’ written responses to the questionnaire submitted in the period between December 2020 and August 2021. In September 2021, an HCP involved in the treatment of patients at the neuro-oncology department received a list of patients’ hospital identification numbers provided by the hospital’s IT department, which automatically registered the names of the patients who completed the questionnaire. The list consisted of patients who had started to fill in or completed the questionnaire. Because of the HCP’s involvement in treatment of the patients, the HCP had access to the electronic health records of the listed patients.

Patients’ written answers to the questionnaire were included using a sampling strategy that was based on choosing every second questionnaire on the list provided by the IT department during 3 sessions. The HCP accessed the written patient answers

through the electronic health record and extracted data by pseudoanonymizing them into plain text fragments. To protect privacy, the treating HCP (TS) provided the researchers with anonymized patients’ answers, excluding information such as names, locations, and work specifications. Patients’ characteristics were collected by the treating HCP and were also presented to the researcher (JHKB).

The questionnaires were included based on their number and eligibility. They were eligible when the patients’ written answers were submitted between December 2020 and August 2021 and if the patients were still under treatment at the neuro-oncology department. The HCP did not extract written patient answers if the main treating physician was not from the neuro-oncology department. If written patient answers were not eligible, the HCP used the patient’s identification number next on the list and assessed whether the written patient answer to the questionnaire was eligible.

Data Analysis

The aim of the analysis was to understand how patients interpreted the questions and whether their answers would help HCPs to get to know their patients. Therefore, we used a content analysis approach to study the answers provided by patients [14]. We decided that the level of analysis was themes and predefined a set of categories based on the 5 questions in the survey. A researcher (JHKB) with qualitative research experience collated the answers of patients by survey question and read the answers carefully. The aim was to identify how the patients used the categories (survey questions), which would allow us to decide the usefulness and interpretability of the survey questions. Therefore, the collated answers were coded, and themes were identified. A coding tree was developed using NVivo Pro (QSR International), allowing for both deductive (predefined categories based on survey questions) and inductive codes. The inductive codes were added to reflect themes the respondents frequently addressed; they were added throughout the coding process. Practically, the first author conducted most of the work but did so in collaboration with the other authors (HWW, JJMvD, and AJ). Another researcher (HWW), skilled in narrative research, coded half of the patients’ answers independently to allow for coder triangulation. Double-coded text and the resulting coding trees were discussed, and a final

tree was agreed upon. In the next step, the codes were grouped: codes were merged into existing higher-level codes, or new higher-level codes were created to group lower-level codes. Saturation was achieved at the level of main themes. The preliminary results were also discussed with the patient panel.

The quotations used in this paper were translated into English; the original quotes were in Dutch.

Ethical Considerations

Owing to the anonymized and retrospective nature of the study, ethics approval from the REC was not necessary according to Dutch law.

Results

Description of the Sample

According to the IT register, 374 patients received an invitation to complete the questionnaire between December 2020 and August 2021. Overall, 20.9% (78/374) of the patients completed the questionnaire and saved their written answers. Between December 2020 and April 2021, when patients were personally selected by HCPs for the questionnaire, 41, (41/374, 10.9%)

patients received the questionnaire, 54% (22/41) answered the questions, and none (0/41, 0%) completed the questionnaire more than once.

From May 2021 to August 2021, a total of 333 (333/374, 89%) individuals were automatically provided access to the questionnaire based on a financial label of the diagnosis-treatment combination in their electronic health record. Of this group, 16.8% (56/333) of the patients completed it.

A sample of 42 (54%) written answers was selected from 78 completed questionnaires. Of this sample of 42 patients, 1 (2%) had not completed a single question, 3 (7%) answered 4 questions, and 1 (2%) answered only question 1. All 5 questions were answered by 88% (37/42) of the patients. All patients (42/42, 100%) completed the questionnaire for the first time, and none of them (0/42, 0%) completed the questionnaire more than once. The characteristics of the 42 patients are presented in [Table 2](#). Log data were not registered by the hospital. Therefore, information about patients' duration for completing the questionnaire, how often and for how long the information button was used, and how often and for how long an HCP looked at the questionnaire could not be collected.

Table 2. Patient characteristics (n=42).

Characteristics	Values, n (%)
Sex	
Male	20 (48)
Female	22 (52)
Age group (y)	
<40	8 (19)
40-50	4 (10)
51-60	16 (38)
>60	14 (33)
Type of disease	
Meningioma	8 (19)
Glioma	26 (62)
Glioblastoma	19 (45)
Brain metastases	5 (12)
Other	2 (5)
Unknown	1 (2)
Recurrence of the disease	8 (19)

General Impression About the Written Answers

The average use of words was quite similar for all 5 questions, but there was a spread in the number of words that patients used. The numbers are presented in [Table 3](#). Almost all patients were able to answer the questions and provided personal information.

Most patients' answers were intelligible and interpretable. In some cases, the interpretation was more difficult. For example, a person did not use punctuation, and another person seemed distrustful, possibly as a consequence of their neurological condition.

Table 3. Word count.

Questions	Average length of answers (words) ^a	Number of words used, median (IQR)	Spread of words ^b , range
1—What are important activities, now or in the future?	25	12 (7-29)	1-298
2—Which people are important in your life, and why are they important?	25	15 (6-24)	0-218
3—What are you worried about concerning your health?	27	17 (8-25)	0-220
4—What do you think is important that your health care professionals know about you?	33	16 (9-38)	0-280
5—What do you expect from your treatment at the [large academic hospital]?	20	17 (7-24)	0-90

^aValues are rounded to the nearest whole number.

^bVariation between the number of words used in the written answers.

Nearly all patients stayed close to the topic of the questions. Only in a few cases, a part of the answers entailed a topic that did not directly relate to the question and included extra, personal information. Overall, 4 (10%) of the 42 answers were elaborate, consisting of >200 words.

Most patients described things that were specific to their situation. They provided additional information, such as the name and age of their children, specific activities, personal concerns, or information about their individual situation. Some patients wrote more concisely, using general language.

Question 1: What Are Important Activities, Now or In the Future?

When answering the first question, many people wrote about leisure activities and other social activities. Sports and family activities were mentioned most frequently. Slightly less than half of the respondents wrote about their job as an important activity. Some described driving a car or doing housework independently. A part of the respondents wrote about activities they wanted to do or keep doing in the future:

Being able to keep doing the daily housework chores including buying groceries. Exercise and cycling and going for a walk. Going on a trip with the camper (I do not drive myself). Maintaining social relationships and participating in the [organization]. [Participant 18]

Some patients did not mention a specific activity but wrote about "maintaining normal activities" or "being independent."

Question 2: Which People Are Important in Your Life, and Why Are They Important?

The people considered to be most important were the partner, children, family, and friends. Other people mentioned were colleagues, neighbors, and other acquaintances.

More than half of the patients provided a reason why particular people were important. Respondents noted different reasons, varying from "loving the person," "being physically and/or mentally supported by them," or "having fun together":

My (grand)children ([number of] sons, [number of] daughters in law, [number of] grandchildren, [number] on its way). They are my everything, I am

incredibly proud of them. [They give me] support and care with lots of things, vice versa. [Participant 14]

Question 3: What Are You Worried About Concerning Your Health?

The most frequently expressed worries were about the possible influence of the disease on the patient's life. Some patients were concerned about their health declining in general. People were worried about the development of specific physical complaints, such as brain damage, decrease in energy level, or neurological deficits. Some explicitly mentioned that they were worried about how treatment would affect their lives; others mentioned the possible influence of the disease on their loved ones. In addition, some wrote about the fear of cognitive impairment, fear of "not being themselves anymore," or being scared to "lose control of their minds." In addition, the influence of the disease on undertaking activities was mentioned. People worried about whether they would still be able to do their job, live independently, or stay mobile:

My disease and the uncertainty it brings. Will I be able to do my job the way I used to do it? How will the process [of working again] go? Will I be my old self regarding my energy level and will I be a nice partner for my girlfriend and a good father for my son? [Participant 7]

Some worried about the disease itself. They felt that the tumor was a "thing" that was not supposed to be there and used language that referred to their disease as an entity on its own.

Some answers were about "getting better." People were worried about whether the disease was curable and whether "everything would be alright" or that they may not have "enough time." Furthermore, a general fear about what the future has in store was seen.

A few of the patients shared that they had no concerns, and a person explicitly did not answer the question because they wanted to stay positive. Some patients wrote the worries that they prioritized:

Physical [issues] do not bother me too much at the moment, I can cope with anything as long as I can be myself and my brain keeps working properly. Another great worry is that soon I won't be able to function

anymore and so as a freelancer I won't have a job, income or insurance. [Participant 31]

Question 4: What Do You Think Is Important That Your HCPs Know About You?

Preferences regarding health care were frequently mentioned. An important topic was communication preferences. Respondents wrote about “clear or transparent communication” and “explaining medical information,” sometimes with pictures. Some noted that they wanted “to be addressed casually.” A number of patients wanted to take someone with them to the consultation:

I want to be addressed informally[.] I like it when people use humor and make jokes, also about my disease and treatment[.]...I want people to be honest with me and my partner about the treatment and prognosis[.] Openness and honesty is important to me. [Participant 10]

In addition to discussing communication preferences, patients provided insight into their needs from and attitude toward treatment and overall health care. Some wrote that they would do anything to stay as healthy as possible, whereas a patient described the importance of having a choice:

I do not want to get every treatment, I want to think about the treatment and I want to have a choice... [Participant 3]

In addition to preferences, some provided HCPs with personal information. They described how they felt, for instance, being nervous or feeling shocked by the test results. Patients also wrote about their social situation, personal characteristics, previous diseases, or current physical situation.

Question 5: What Do You Expect From Your Treatment?

Approximately half of the patients wrote about expectations regarding their treatment goals. Some wrote about “the removal of the tumor” and the hope for “curing the disease”, or they wanted “the treatment to be effective”. A few were afraid of possible side effects:

First of all the removal of the [disease]. And that the treatment does not cause long-term harmful side effects. I don't want to suffer from nasty side effects of a treatment like I did [number] years ago. [Participant 13]

Some mentioned that they hoped to “go back to their normal lives” or wanted to “maintain quality of life.” Wishes regarding the end of life were also written. Some wanted their HCP to be professional or wanted their close ones to be involved in their care. A few specifically expected guidance from HCPs throughout the care process.

Communication was mentioned as an important topic in the answers to both questions 4 and 5. Some patients expressed their desire for “clear, transparent” communication or wrote about a regular point of contact:

It is nice to talk to the same person every time, but I am aware that this is not always possible. I always

want to know what is going on with me, openness and clarity. Even if you cannot give me an answer yet, otherwise I cannot deal with it, let alone accept “it.” And yes, I want to be able to contact you for when I am having questions, it doesn't really matter how. [Participant 14]

Information Button

Some written answers used the same words or suggested the same topics as those in the text of the information button (Table 1). For question 4, approximately one-third of the patients specifically mentioned their wish to bring someone to the consultation. Others wrote that they wanted to be addressed informally or wanted an HCP to show pictures while explaining the medical information.

Slightly less than half of the respondents wrote about the result of the treatment while answering question 5, and a few patients mentioned a regular contact person. A person seemed to directly react to the information button:

I already have a regular contact person, very nice. Pull out all the stops to get better. [Participant 9]

Discussion

Principal Findings

This study showed that patients addressed a variety of topics related to their care. Frequently mentioned topics for important activities were leisure activities, such as social activities or sports. Some mentioned their job, and others wrote more generally about maintaining normal activities. Many respondents said that their partner, children, other family members, and friends were important people. If patients provided a reason why these people were important to them, they often wrote about loving the person or feeling supported by them. The possible influence of the disease on their health was a concern expressed most frequently by the patients. The written answers contained concerns about the effect of the disease on their physical and mental health or the effect on undertaking activities. Getting better in general was also an issue that was mentioned. For some, the tumor itself, being a thing that does not belong in someone's head or body, made them anxious. Others wrote about fear of the future in general. The respondents wanted their HCP to know about their health care preferences, such as their treatment goals or communication preferences. Others shared information about their personal life, such as their social situation, personal characteristics, or physical situation. Expectations regarding effective treatment and the care process, including HCPs' attitudes, the involvement of close ones, and decision-making, were emphasized.

This content appears to be relevant for health care, even if it is not always surprising. The addressed topics show similarity with the important factors regarding patients' perception about high-quality communication [15-18]. The questionnaire provides an opportunity for patients to think about what they consider important for their health care. Moreover, it can help HCPs to follow up on these topics during the consultation. The questionnaire can be a starting point for HCPs to explore patients' wishes, needs, and preferences relevant for a

person-centered approach to care, allowing for a phenomenological approach to illness, to supplement the traditional, naturalistic medical approach.

Our results show similarities to the results of the study by Zwakman et al [19]. Zwakman et al [19] conducted a content analysis of a preference form as part of advance care planning for patients with advanced stage cancer. The preference form has questions that are comparable with questions 1, 3, 4, and 5 of this study. Both in the study by Zwakman et al [19] and in this study, maintaining a normal life and doing everyday activities were important topics. Moreover, patients valued spending time with family and friends. In both studies, patient populations expressed concerns about the effect of the treatment and the disease's progression. Furthermore, staying independent and clear communication were important topics. However, in our study, respondents wrote less about end-of-life arrangements and alternative treatment options, possibly owing to the difference in treatment phase. Patients expressed a more precise expectation regarding their care in our study, perhaps because the question was asked more directly.

Overall, approximately 20.9% (78/374) of patients completed the questionnaire. Between December 2020 and April 2021, the percentage of completed questionnaires was higher, namely 54% (22/41). In this first phase, an internal assessment was conducted, in which the questionnaire was actively promoted. The low response percentage after April 2021 suggests that HCPs' awareness is important and can stimulate patients to complete the questionnaire, making the questionnaire potentially more usable. Other reasons that could have influenced the response percentage were unawareness of the patient portal, difficulties in finding the questionnaire, or not wanting to answer the questions.

The selected sample showed an average word count of approximately 26 words per question, and the median number of words used was between 12 and 17. Time constraints for HCPs are a known barrier to the implementation of PCC interventions [20,21]. In this sample, patients mostly used a limited number of words, making it easy to read quickly for HCPs. Most patients were able to respond to the 5 questions and wrote an interpretable answer. Most stayed close to the topics of the questions, and some patients wrote additional information.

The information button was developed to provide guidance to patients. Our results suggest that the information buttons might influence the patients' answers. The respondents sometimes write about particular topics mentioned in the information

button, such as bringing a person to the consultation, explaining medical information with pictures, talking about a regular contact person, or having expectations about the result of treatment. Altering the text of the information button could improve the relevance of the information the questionnaire yields regarding daily health care. An example could be adjusting the information button's text for question 4 by adding treatment preferences as a suggested topic.

Strengths and Limitations

The strength of this study lies in the data and the thoroughness of the content analysis. Apart from the anonymized parts of the text, we used the patients' exact words and punctuation as the treating HCP would read it. Moreover, we assessed the answers to the questionnaire regarding concise versus detailed writing and digression from and elaboration about the topic and estimated the ease of interpretation.

This study also had some limitations. First, this patient population is specific. Patients with neuro-oncological conditions have a very serious, often life-limiting disease that requires high-intensity care. It is possible that other topics found in this study may be different for other patient populations. Second, patients included in this study were affected by different histological diagnoses with therefore different prognoses and treatments for their diseases. In this study, this was not analyzed specifically. Third, our sample size of 42 patients is limited. Nevertheless, it still provides useful insights and can help to elucidate the questionnaire's ability to improve PCC in daily health care.

Conclusions

This questionnaire helps to stimulate patients to write about things that they consider important. By reading the patient's answers before the consultation, HCPs can start the medical encounter with more insight into what matters to the patient. This is a major component of what determines the quality of care according to patients [22] and thus may facilitate care to become truly person centered.

This study can help the further development and implementation of the questionnaire, for instance, by adjusting the information buttons. For future studies, it may be important to repeat the questionnaire later in the care process to evaluate the possible changes in patients' answers. The questionnaire could benefit from future studies that focus on the experiences of patients and HCPs with the questionnaire, its possible effect on the medical consultation, and the evaluation of facilitators of and barriers to its implementation in daily health care practice.

Data Availability

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

Authors' Contributions

JHKB contributed to the design of the study, collected the data, analyzed and interpreted the data, drafted the paper, and approved the final paper as submitted. HWW contributed to the design of the study, analyzed and interpreted the data, critically reviewed and revised the paper, and approved the final paper as submitted. TS contributed to the collection of the data, critically reviewed and revised the paper, and approved the final paper as submitted. AJ drafted and edited the paper with a special focus on

methodology and approved the final paper as submitted. JJMvD contributed to the design of the study, interpreted the data, drafted and edited the paper, and approved the final paper as submitted.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Format of the "We would like to know you" questionnaire administered to patients.

[\[DOC File, 81 KB - jopm_v16i1e48573_app1.doc\]](#)

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Abbreviations

HCP: health care professional

PCC: person-centered care

SDM: shared decision-making

Edited by J Wald; submitted 01.05.23; peer-reviewed by A Oostdyk, M Wright, R Marshall; comments to author 30.06.23; revised version received 08.11.23; accepted 03.01.24; published 04.03.24.

Please cite as:

Bergers JHK, Wessels-Wynia H, Seute T, Janssens A, van Delden JJM

Getting to Know Your Patient: Content Analysis of Patients' Answers to a Questionnaire for Promoting Person-Centered Care
J Particip Med 2024;16:e48573

URL: <https://jopm.jmir.org/2024/1/e48573>

doi: [10.2196/48573](https://doi.org/10.2196/48573)

PMID: [38437017](https://pubmed.ncbi.nlm.nih.gov/38437017/)

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Original Paper

Investigating Patient Satisfaction Through Web-Based Reviews of Norwegian Dentists: Quantitative Study Using the Meaning Extraction Method

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Abstract

Background: Challenging encounters in health care professions, including in dentistry, are relatively common. Challenging encounters can be defined as stressful or emotional situations involving patients that could impact both treatment outcomes and patients' experiences. Through written web-based reviews, patients can share their experiences with health care providers, and these posts can be a useful source for investigating patient satisfaction and their experiences of challenging encounters.

Objective: This study aims to identify dominant themes from patient-written, web-based reviews of dentists and investigate how these themes are related to patient satisfaction with dental treatment.

Methods: The study data consisted of 11,764 reviews written by dental patients, which included 1- to 5-star ratings on overall satisfaction and free-text comments. The free-text comments were analyzed using Linguistic Inquiry and Word Count software, and the meaning extraction method was used to group words into thematic categories. These themes were used as variables in a multilevel logistic regression analysis to predict patient satisfaction.

Results: Eight themes emerged from the analyses, of which 6 (75%)—*explanation* (odds ratio [OR] 2.56, 95% CI 2.16-3.04; $P<.001$), *assurance* (OR 3.61, 95% CI 2.57-5.06; $P<.001$), *performance assessment* (OR 2.17, 95% CI 1.84-2.55; $P<.001$), *professional advice* (OR 1.81, 95% CI 1.55-2.13; $P<.001$), *facilities* (OR 1.78, 95% CI 1.08-2.91; $P=.02$), and *recommendation* (OR 1.31, 95% CI 1.12-1.53; $P<.001$)—increased the odds of high patient satisfaction. The remaining themes (2/8, 25%)—*consequences of treatment need* (OR 0.24, 95% CI 0.20-0.29; $P<.001$) and *patient-centered care* (OR 0.62, 95% CI 0.52-0.74; $P<.001$)—reduced the odds of high patient satisfaction.

Conclusions: The meaning extraction method is an interesting approach to explore patients' written accounts of encounters with dental health professionals. The experiences described by patients provide insight into key elements related to patient satisfaction that can be used in the education of dental health professionals and to improve the provision of dental health services.

(*J Particip Med* 2024;16:e49262) doi:[10.2196/49262](https://doi.org/10.2196/49262)

KEYWORDS

internet use; Linguistic Inquiry and Word Count; LIWC; patient satisfaction; patient preference; challenging encounters; preventive dentistry; population surveillance

Introduction

Challenging Encounters and Patient Satisfaction

Challenging encounters in health care are not uncommon [1,2] and can be defined in various ways by individual health care providers [3]. Situations such as dealing with violent patients, “breaking bad news,” and managing demanding family members are examples of challenging situations mentioned by health care providers [4,5]. Health care providers have also referred to patients they perceive as challenging as the source of conflict, and anxious or angry patients are most often mentioned as challenging [4,6]. Studies have also defined challenging encounters as situations where patients are “causing negative feelings in physicians” [7], and challenging encounters between health care providers and patients have been linked to increased burnout and stress among health care providers [2,8]. This issue is also highly relevant in dentistry, and dentists have reported that up to 25% of their daily encounters are perceived as challenging [6]. While studies have addressed how health care providers define and experience challenging encounters, the patient experience has been explored to a lesser extent. Whether a patient has experienced a challenging encounter could be researched through use of patient satisfaction measures.

Patient satisfaction has been defined in many different ways in research through the years. In a recent literature review [9], three main definitions of patient satisfaction were identified: (1) the patients’ experience based on their expectations of a health care service and how the service met their expectations, (2) patient satisfaction defined as feedback forming the basis for the improvement of health care services, and (3) patient satisfaction defined as the patients’ perception of health care providers’ ability to provide proper care and the quality of the interpersonal relationship. Research investigating patient satisfaction has revealed inconsistent results regarding the establishment of important determinants [10]. This might be due to differing definitions of the concept of patient satisfaction among studies [9,10]. In addition, in most studies, patient satisfaction is generally reported as high; however, this could be an overstatement due to limitations in the data collection instruments, and it has been suggested that including measurements of patient dissatisfaction in the instruments may help produce a more correct picture [10]. Arguably, there is a need to include issues relevant to patients that are not predefined by health care personnel or researchers [9]. A recent literature review has criticized current methods for evaluating patient satisfaction in health care, arguing that they seem to have been adopted from consumer satisfaction models and could therefore be inappropriate in health care settings [9]. Research has shown that the most important predictor of patient satisfaction is high-quality patient communication [11]. In addition, what seems most important to patients when indicating satisfaction is the relationship between the patient and the health care personnel, as well as the perceived social abilities of the health care personnel [12]. Furthermore, a link has been found between patient satisfaction and the performance of dental health professionals [13]. Other issues, such as the availability of services (including short waiting times, access to local hospitals, and ample parking) and the technical performance of the health

care personnel, seem to matter less while still remaining important determinants of patient satisfaction [12].

Internet Research and Health Care Services

The internet provides almost unlimited user-generated content available for research, and for health researchers, it presents the opportunity to investigate the general public’s opinions and knowledge on a myriad of topics, including those related to health [14,15]. These data also enable research on social interactions (eg, the interactions between caregivers and users in web-based treatment procedures [15] through the use of natural language processing [NLP] [16]). NLP refers to the use of computational models on natural text materials to study associations between language and other variables, including the prediction of behavior or other outcomes. It is used widely in several disciplines (eg, opinion mining in sales and marketing services [14] as well as research on user-written reviews of experiences and products [17]). The methods within the field of NLP can also be used to investigate interesting health-related aspects, such as the detection of signs of clinical depression [18] and social anxiety [19]. In the broader context of health care, topics such as users’ opinions, experiences, and health literacy and competence are relevant to investigate with NLP [15]. In addition, patient-written reviews of health care services could present a major source of information relevant to health care workers.

There are currently many websites that provide patients with the opportunity to rate and write about their experiences with health care providers. While the use of social media as a platform for health communication is generally considered a powerful tool for both patient and health care providers [20], web-based reviews of health care services and health care providers might provide unique insight into the experiences of patients and their evaluations of the quality of health services [20]; for example, in recent research investigating the web-based reviews of an obstetric care clinic, it was found that patients’ experiences of the quality of the facilities and the perception of staff as comforting and providing high-quality care were associated with increased patient satisfaction [21]. Compared to other means of providing feedback to health care professionals, web-based reviews have benefits such as perceived anonymity and freedom from potentially negative consequences of evaluating figures of authority. Further benefits can be related to the social dimension of disseminating one’s views, experiences, and opinions to peers [20]. However, some challenges are also apparent, such as the subjectivity and contextual nature of web-based reviews [22] as has been found for other web-based evaluations related to health care [23].

Web-Based Evaluations of Dentists

While numerous studies have examined web-based ratings of physicians [9], few have examined web-based ratings of dentists. In a study of web-based evaluations of dentists in Germany, it was found that rating scores were largely positive and that younger or female dentists provided the most positive ratings [24]. In addition, differences in ratings emerged among clinical specialties, with pediatric dentists receiving better ratings than orthodontists [24]. Furthermore, a study published in the United States showed that younger or female dentists received the best

web-based reviews, as did dentists where patients experienced shorter waiting times [25]. Studies also point to specific topics that seem to influence evaluations, such as experiences of discomfort perceptions of a lack of professional ethics [25], and topics that might be specifically related to challenging encounters or negative evaluations of dentists on the web [26]. Interestingly, negative web-based reviews about dentists, while uncommon [24,26], are perceived as more trustworthy than positive reviews [27].

Considering these findings and challenges, this study aims to investigate how the content of web-based reviews of dentists in Norway can be used to predict patient satisfaction and challenging encounters, indicated by high and low rating scores, respectively, through the following steps: (1) identify dominant themes discussed by patients in their reviews and (2) investigate the dominant themes and their relationship with patient satisfaction and challenging encounters as rated by the patients.

Methods

Overview

The data were extracted from a Norwegian website that helps patients connect with health care professionals by the administrators of the website and made available to us as a downloadable data dump [28]. On this website, there is an option for patients to write about their experiences regarding receiving health care from dentists, general practitioners, physical therapists, and other health care professionals. A total of 11,764 patient reviews of dentists posted during the period from February 2013 to June 2020 were included in the data set. The patients rated their overall experience using 1 to 5 stars (1=*very unsatisfied* and 5=*very satisfied*) in addition to providing written comments. Patients could also rate other aspects of treatment, such as service, price, and treatment comfort. In addition, information about the date of the post and self-reported visiting frequencies was included. However, in this study, only the written comments and overall rating scores were used in the analysis.

Language Analysis and Theme Extraction

The language analysis tool Linguistic Inquiry and Word Count (LIWC; version 2022) [29] was used to analyze the text data. The LIWC is designed to measure psychometric properties in language. As noted by Boyd [30], LIWC analysis typically works best with texts exceeding 50 words (shorter texts with a minimum of 10 words may still yield some insights, but the results may be less accurate). This is because LIWC dictionaries work by calculating the relative percentage of a word's occurrence in a body of text. In our analysis, the Norwegian LIWC 2007 dictionary was used [31]. By applying the meaning extraction method (MEM) through the LIWC's built-in meaning extraction helper, we could determine the dominant word categories used in the reviews. A detailed description of the principles behind the MEM can be found elsewhere [30]; however, in the following subsections, we will describe the process in detail as it relates to this data set.

Analysis Inclusion Criteria: Text Length and Word Frequencies

The free text of the comments section of the 11,764 reviews was run through the meaning extraction helper. Each review consisted of a header and a main comment. In the analysis, all words with raw frequency of >2% were retained. The decision to use 2% instead of 5%, as recommended by Boyd [30], was due to the large number of small texts in our data set. Specifically, we found that a large number of words would appear in <5% of the material because each comment was analyzed as a single text. Hence, a 5% cutoff would exclude too many words, whereas the cutoff value of 2% provided sufficient removal of uncommon words. Each comment posted on the aforementioned Norwegian website needed to be at least 100 characters long, including punctuations and spaces. Even so, to avoid including text that would not provide any meaningful information to the content analysis (eg, exclamatory remarks such as "Great dentist!" with no further information other than signs or emojis), the inclusion criterion for the length of reviews included in the analysis was set to >5 words. To ensure meaningful results, the header was removed from further analysis because it often duplicated words used in the main comment. This could have created a false emphasis on certain commonly used phrases.

Lemmatization List and Stop List

The MEM relies on the process of lemmatization, which requires a lemmatization list and a stop list. These were created following the recommendations from previous research [30,32,33]. The lemmatization list converts commonly used words to their word stem to count words correctly (Multimedia Appendix 1). The stop list omits words from further analysis, and the words chosen to be omitted would typically be words that were of no interest to the research question, such as the names of geographic locations, the word "dentist" (as we would expect it to be present in almost all comments), or numerical words. In addition, some function words, such as selected personal pronouns, conjunctions, and prepositions, were omitted ahead of analysis because they appeared often and could therefore dilute important content words. Examples of function words and other words omitted can be found in the stop list (Multimedia Appendix 2). Words included in the analysis were verbs, adjectives, adverbs, nouns, and all function words that were not included in the stop list. Care was taken not to omit too many words to preserve the rawness of the data. In addition, because internet-based language often adopts an informal, conversational style, resembling speech [34], we needed some function words to be retained, although some recommend that they be removed completely [30].

Exploratory Factor Analysis

The results provided from the MEM were used to perform an exploratory factor analysis [35] using SPSS (version 28.0; IBM Corp). The MEM analysis provided a binary matrix for all reviews, which included a value of 1 if the words appeared in the review and 0 if not. The Bartlett test of sphericity and the Kaiser-Meyer-Olkin test of sampling adequacy were performed to test whether the MEM results were suitable for factor analysis. Varimax rotation was used to extract uncorrelated factor items

with a factor loading threshold set to >0.2 based on the recommendations made by Markowitz [33]. Determining the number of factors to extract was based partly on an inspection of the scree plot (ie, the identification of the elbow of the plot) and eigenvalues (>1), as well as on the proposed factors' interpretability. Words that had cross-loadings of >0.2 were omitted.

The words contained within the factors were then added to the Norwegian LIWC dictionary [31] as separate word categories. The complete data set was run through the LIWC analysis using the modified dictionary. The LIWC gives information for each review in terms of the percentage of words that matches the dictionary word categories.

Multilevel Logistic Regression Analysis

To determine how the retrieved factors could predict patient satisfaction, a 2-level (dentist and review) random intercept logistic regression model was built, with *high patient satisfaction* as the outcome. *Patient satisfaction* was the overall rating variable recoded to a binary variable, whereby ratings of either 4 or 5 stars signified *high patient satisfaction*, and ratings of 1, 2, or 3 stars signified *low patient satisfaction*. The 8 factors (the aforementioned 8 themes) were entered as covariates recoded into binary variables—*frequent use* versus *infrequent use* or *use* versus *no use*—with the median as cutoff value (with median=0 being recoded as *no use*). A multilevel analysis was chosen as the reviews were not statistically independent variables because

they could be commenting on the same dentist. The multilevel logistic regression analysis was performed in MLwiN (Centre for Multilevel Modelling, University of Bristol) [36]. The results are reported as regression coefficients, odds ratios (ORs), and respective 95% CIs. The variance partition coefficient (VPC) was also reported. The VPC estimates the proportion of the total variance in positive versus challenging encounters attributable to differences among dentists. The VPC is given as $\sigma^2_{u0}/(\sigma^2_{u0}+\Pi^2/3)$ [37].

Ethical Considerations

All reviews were posted on the Norwegian website [28] voluntarily, and the data set provided by the website administrators contained only anonymous data. The study was approved by the Norwegian Centre for Research Data (468642).

Results

Overview of the Data

A description of the demographics of the data set can be viewed in Table 1. The mean word count of each review was 48.9 (SD 39). More than nine-tenths of the reviews (10,977/11,764, 93.31%) had a high rating score (4-5 stars), whereas the remaining reviews (687/11,764, 5.84%) had a low rating score (1-2 stars). A total of 2950 dentists had received a rating in our data set, and the mean number of reviews per dentist was 3.9.

Table 1. Age and sex distribution of dentists and patients.

	Dentists (n=2950), n (%)	Patients (n=11,764), n (%)
Age (y)		
<20	0 (0)	64 (0.54)
20-30	74 (2.51)	2017 (17.15)
31-40	710 (24.07)	1947 (16.55)
41-50	823 (27.90)	1417 (12.05)
51-60	591 (20.03)	1098 (9.33)
>60	751 (25.46)	755 (6.42)
Missing	1 (0.03)	4466 (37.96)
Sex		
Male	1597 (54.14)	3407 (28.96)
Female	1328 (45.02)	4235 (36)
Missing	25 (0.85)	4122 (35.04)

Exploratory Factor Analysis

The exploratory factor analysis identified 8 factors (Textbox 1) that will be described in the following subsection. The Bartlett test of sphericity was significant ($P<.001$), and the Kaiser-Meyer-Olkin measure of sampling adequacy was 0.66.

The factors extracted together explained 13.2% of the sample variation, and they were thematically labeled based on a theoretical understanding of the words they contained: *consequences of treatment need, explanation, assurance, facilities, recommendation, patient-centered care, professional advice, and performance assessment.*

Textbox 1. Factors and factor loading (%) for words from the exploratory factor analysis.

Consequences of treatment need (eigenvalue: 3.205)

- Receive: 0.479
- Tooth: 0.478
- Must: 0.421
- Become: 0.421
- Come: 0.356
- Go: 0.350
- Caries: 0.314
- Sat: 0.296
- Because of: 0.283
- Back: 0.274
- Bad: 0.273
- Same: 0.261
- Ache: 0.258
- New: 0.254
- Wanted: 0.249
- Day: 0.244
- Pain: 0.242
- Anesthetics: 0.241
- Where: 0.239
- Enough: 0.225

Explanation (eigenvalue: 2.087)

- To do: 0.632
- Explain: 0.571
- Why: 0.386
- Good: 0.258
- Tell: 0.249
- Thorough: 0.205

Assurance (eigenvalue: 1.863)

- Feel: 0.881
- Safe: 0.676
- Take care of: 0.613
- Hands: 0.369

Recommendation (eigenvalue: 1.777)

- Recommend: 0.787
- Strongly: 0.484
- Warm: 0.466
- Could: 0.375
- Absolutely: 0.230
- Really: 0.226
- Unbelievable: 0.201

Facilities (eigenvalue: 1.671)

- Modern: 0.774
- Equipment: 0.751
- Premises: 0.507

Patient-centered care (eigenvalue: 1.571)

- Take: 0.789
- Consideration: 0.453
- Care: 0.433
- Patient: 0.263

Professional advice (eigenvalue: 1.511)

- Give: 0.505
- Advice: 0.403
- Information: 0.337
- Treatment: 0.325
- Very: 0.263
- Profoundly: 0.223
- Pleased: 0.217
- Amazing: -0.230
- Professional: 0.200

Performance assessment (eigenvalue: 1.456)

- Quick: 0.495
- Efficient: 0.428
- Nice: 0.348
- Wisdom tooth: 0.260
- Job: 0.241
- Forthcoming: 0.234

Dominant Themes Identified by the Analysis

Consequences of Treatment Need

The theme *consequences of treatment need* seemed to contain words related to the patients' need for treatment, with mentions of dental health issues such as dental caries ("tooth" and "caries"). In addition, other words associated with this theme seemed to express the urgent need to obtain an appointment ("must," "receive," "new," "come," and "go"), as well as words that might be related to an explanation of what happened ("back," "because of," "same," and "where"). The word "must" could be related to the feeling of a lack of self-agency and self-determination in the situation, for example, in this quote, where the patient might have felt that they had no control of the situation:

When I first got there, she seemed friendly, but that was before the treatment started. During treatment she had no consideration and continued even though I was crying in the chair. [Example 1]

In this theme, many words were action related (verbs), in the sense that something happened or certain actions were performed ("go," "receive," and "become"); for instance, patients would sometimes explain the turn of events resulting in a dentist appointment or their reasons for either seeking dental treatment or writing about the dental encounter. Arguably, it could also be the case that these words were related to the feeling of unmet expectations ("wanted" and "enough"). Typically, patients would often describe themselves as experiencing dental anxiety, which contributed to an uncomfortable treatment situation:

He got annoyed and asked very rudely what my problem was. Well yeah mister I have dental phobia! DO YOU EVEN KNOW SOME PEOPLE SUFFER FROM THIS? I stopped the treatment and paid 450 NOK for him to be rude to me. Still on the lookout for a good dentist who can deal with people like me. Don't go to him if you have this phobia! [Example 2]

Explanation

The theme *explanation* contained words such as “explain,” “tell,” and “why.” From the other prevalent words in this theme (“thorough,” “good,” and “to do”), it could be argued that patients used these words to describe instances where the dentist thoroughly explained the treatment or other topics, as exemplified by this quote:

[Name] adapts the treatment, stops and gives you small breaks during treatment, check that you feel okay, she is very good at explaining what is going to happen and what she does during treatment. [Example 3]

Assurance

The theme *assurance* contained words related to safety and care (“safe,” “take care of,” “hands,” and “feel”) as experienced in relation to the encounter between patient and dentist:

You feel like you are in good hands. A cheerful and pleasant lady! Your dental fear disappears when you sit down and she begins to talk. [Example 4]

Facilities

The theme *facilities* contained the words “modern,” “equipment,” and “premises,” which indicates that patients specifically noticed the environment of the dental clinic:

Shows and explains to you using modern equipment. I strongly recommend him. [Example 5]

Got no information about cost and got yelled at for not using them last time (dental emergency office—I have a regular dentist) bragged about the expensive equipment, where I had to pay 900 NOK for a picture I didn't need. [Example 6]

Recommendation

The theme *recommendation* contained words related to the need to disseminate the patients' views of the dentist to others, with words such as “recommend” and “strongly”:

I recommend him to everyone I know with toothache. [Example 7]

I strongly recommend this dentist! [Example 8]

Patient-Centered Care

The theme *patient-centered care* contained words related to patient-centered care or the experience of empathetic behavior from the dentist (“take,” “care,” “patient,” and “consideration”). It would be tempting to think that this theme would be linked to *high patient satisfaction*, but the words could also be used to express how the patient would have liked to be treated; for instance, in the following quote, we see how the words related to patient-centered care were used when the patient expressed experiencing a lack of patient centeredness:

It is distressing that there are dentists that have so little consideration for their patients. When you are in a vulnerable situation beforehand, then this is the last thing you need. It is not just teeth they are working with, but humans! [Example 9]

In any case, we noted that patients often wrote about patient centeredness and found it important to experience that the staff and dentist were comforting.

Performance Assessment

The theme *performance assessment* contained words describing the perceived performance of the dentist, an inference to how they performed and the quality of the performance. Here, we find words such as “nice,” “quick,” “efficient,” and “wisdom tooth.” Patients writing the reviews seemed to value their time, and efficient dentists (those completing procedures quickly) were viewed more favorably than dentists perceived to be inefficient at managing their time:

Removed all 4 of my wisdom teeth in a total of 31 (!!!) minutes. 18 minutes the first time and 13 minutes the second time. Do I have to say more? Great experience! [Example 10]

I was not impressed when I went to [name]. I think he spends too much time treating relatively simple issues. Had some complications with a dental restoration that he did which never really got better. [Example 11]

Interestingly, dentists who were perceived as careless or too quick may risk increasing the likelihood of posttreatment issues for patients:

Rushed through the appointment, did not wait long enough to let the anesthetics kick in and drilled right into the nerve, so my head exploded. My dental anxiety that [name; in the same building] had cured came back. [Example 12]

Patients value high-quality work and might feel more pleased with treatment if the dentist acts professionally, is competent, and achieves efficiency without compromising the quality of the treatment.

Professional Advice

The theme *professional advice* consisted of words related to providing information and clinical advice to patients, such as “give,” “advice,” and “information.” It also contained quality assessments of how the advice was perceived or provided, as we can infer from the words “amazing,” “professional,” “pleased,” “very,” and “profoundly.” Patients clearly appreciate professional advice on how to take care of their oral health and their treatment options:

Experience this dentist as skilled, thorough and detail oriented. Gives good information about follow up treatment and what to do at home. [Example 13]

[Name]'s ability to inform about how to treat the post-treatment complications was bad, and the recommended measures had no effect. [Example 14]

Professional, nice and efficient. Good at explaining and I felt safe and taken care of. I got sufficient information ahead of treatment on recommended procedures. Was happy with their follow up on me during treatment and afterwards as well, and how efficient and professional the work was done. [Example 15]

In addition, patients would sometimes express concerns about professionalism, for instance, when they perceived that the personal beliefs of dentists were indistinguishable from professional medical advice:

She tried to push life-threatening antivaccination propaganda on me, without me even bringing up the subject, and what in God's grace does a dentist know about vaccines? And be careful with the double standards all the time she offers Botox treatment (Botox is a nerve toxin). [Example 16]

Predicting Patient Satisfaction

To predict patient satisfaction based on the dominant themes, a multilevel logistic regression analysis was performed (Table 2; Figure 1). Of the total explained variance, 28% was attributable to the differences among dentists (VPC=0.28).

The regression analysis showed that when the patients used words related to *explanation*, the OR for a high satisfaction

score (4 or 5 stars) was 2.56 (95% CI 2.16-3.04; $P<.001$). In addition, if words related to *assurance* were used, the OR was even higher (3.61, 95% CI 2.57-5.06; $P<.001$) for a high satisfaction rating. The odds of a high satisfaction rating also increased with the frequent use of words related to *facilities*, *professional advice*, and *performance assessment* by a factor of 1.77 (95% CI 1.08-2.91; $P=.02$), 1.81 (95% CI 1.55-2.13; $P<.001$) and 2.16 (95% CI 1.84-2.55; $P<.001$), respectively, compared to infrequent use of the respective word categories. This was also the case if patients used words connected to the theme *recommendation*, which increased the odds of the patient being satisfied with dental treatment by 31% compared to when no words related to *recommendation* were used ($P<.001$). By contrast, when patients used words related to the *patient-centered care* theme, the odds of a high satisfaction rating were reduced by 38% ($P<.001$). Similarly, for the theme *consequences of treatment need*, the frequent use of words connected to this theme reduced the odds of a high satisfaction rating by 76% ($P<.001$).

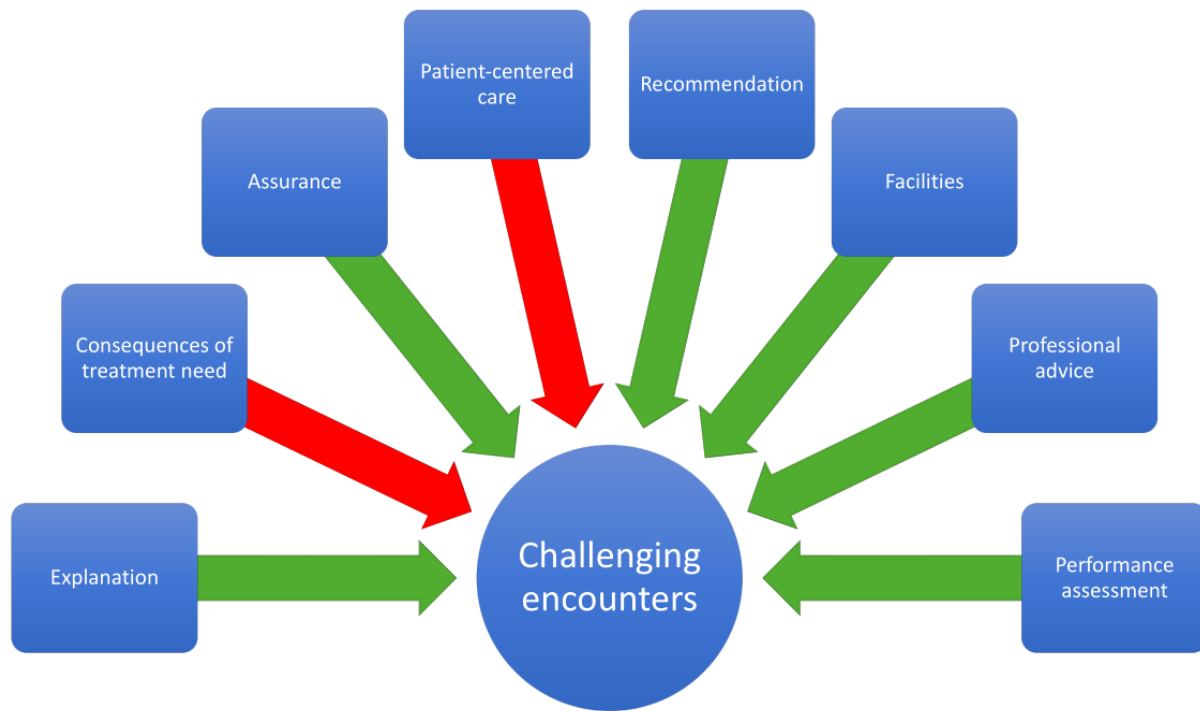
Table 2. A multilevel logistic regression analysis predicting patient satisfaction from dominant themes.

	B (SE)	Odds ratio ^a (95% CI)	P value
Fixed effects			
Intercept, β_{0j}	2.47 (0.11)	N/A ^b	N/A
Themes			
Consequences of treatment need (frequently used vs infrequently used)	-1.43 (0.09)	0.24 (0.20-0.29)	<.001
Explanation (frequently used vs infrequently used)	0.94 (0.09)	2.56 (2.16-3.04)	<.001
Assurance (used vs not used)	1.28 (0.17)	3.61 (2.57-5.06)	<.001
Recommendation (used vs not used)	0.27 (0.08)	1.31 (1.12-1.53)	<.001
Facilities (used vs not used)	0.57 (0.25)	1.78 (1.08-2.91)	.02
Patient-centered care (used vs not used)	-0.48 (0.09)	0.62 (0.52-0.74)	<.001
Professional advice (frequently used vs infrequently used)	0.60 (0.08)	1.81 (1.55-2.13)	<.001
Performance assessment (use vs no use)	0.77 (0.08)	2.17 (1.84-2.55)	<.001
Random effects			
Dentist-level variance	1.13 (0.13)	N/A	N/A
Variance partition coefficient	0.28	N/A	N/A

^aOdds ratio for the patient experiencing a positive encounter when words from the themes are present in the review.

^bN/A: not applicable.

Figure 1. The dominant themes identified and their relation to the challenging encounter. The green arrows indicate that the factor decreases the likelihood of a challenging encounter, while the red arrows indicate that the factor increases the likelihood of a challenging encounter.



Discussion

Eight themes were identified related to patient reviews of encounters with dental health professionals: 6 (75%) were linked to higher patient satisfaction scores and the experience of a positive dental encounter, while 2 (25%) were linked to lower patient satisfaction scores and the experience of a challenging dental encounter.

Principal Findings

If words related to the themes *explanation*, *assurance*, *recommendation*, *performance assessment*, *facilities*, and *professional advice* were present, patients were more likely to rate their experience as satisfying. Conversely, the use of words from the themes *consequences of treatment need* and *patient-centered care* reduced the likelihood of patients rating their experience as satisfying. In the following subsections, we will discuss the results and their implications.

Challenging encounters have been defined earlier in this paper as situations resulting in aversive feelings for dental health professionals [7] and as encounters involving conflicts between the perspectives of dental health professionals and those of the dental patient. In this study, we were interested in the challenging encounter from the dental patients' perspectives, and it was assumed that when patients provided low satisfaction ratings, it indicated the experience of a challenging encounter. Conversely, high satisfaction ratings, it was assumed, indicated the absence of a challenging encounter.

Consequences of Treatment Need

The theme *consequences of treatment need* contained words that could be interpreted as a reflection of unmet expectations, and we found that this theme was associated with an increased

probability of experiencing a challenging encounter. Previous research suggests that some patients might have unrealistic expectations of dental treatment outcomes [38], and it is likely that a disjunction between treatment expectations and perceived treatment outcomes could influence the satisfaction with dental treatment, as indicated by a previous study [19]. However, Yao et al [38] suggest that the studies investigating dental treatment expectations in relation to patient satisfaction do not properly define the term "expectations" and that the results from the studies are diverse and difficult to interpret. This is supported by a recent literature review, which found it difficult to propose a link between patient satisfaction and expectations and suggested that this could be because "expectations" as a concept is not consistently defined in the literature and furthermore that it might be only indirectly associated with patient satisfaction [9].

On the basis of the words used in the *consequences of treatment need* theme, we found that the patients discussed reasons to seek dental health care (eg, "pain" and "caries"), as well as challenges that might have developed (eg, complications and disappointment regarding the outcome). In addition, the patients sometimes expressed feelings that could indicate a lack of self-agency (eg, words and expressions such as "had to," "because," and "caries"), which would indicate that the patients felt that they *had* to see the dentist because of a dental issue or some external cause. Motivations for seeking dental treatment could play a major role in how patients experience the dental treatment. One could envision that the dental encounter would be experienced differently based on the source of the patient's motivation (eg, based on the motivational locus: internal vs external). This closely resembles key features of a problem-oriented visiting pattern, which refers to patients only seeking dental help when faced with acute circumstances (eg,

pain or fractured teeth). This type of attendance has been associated with increased risk of tooth loss [39] and reduced oral health-related quality of life [40] compared to regular attendance. A Finnish study investigating dental patients' perception of their dentist's explanation during treatment found that patients with a problem-oriented visiting pattern and that perceived their economic situation as difficult were more likely to feel dissatisfied with their dentist's explanation skills [41]. It has also been found that individuals with a fear of dental treatment tend to delay treatment and more often report poor oral health [42,43], implying that these patients could often have a problem-oriented visiting pattern. Therefore, it is not very surprising that this theme increases the risk of experiencing a challenging encounter. This could have been avoided if the patients had visited their dentist more often. Different intervention strategies have been used aimed at motivating patients to visit their dentist regularly (eg, community-based dental campaigns and a reduction in expenses) [44]. A recent literature review found that regular attendance could be increased if patients had the opportunity to visit a dental anxiety clinic and receive dental check-ups for free [44]. Such interventions could prove valuable to reduce challenging encounters in the clinic from the patient's perspective.

Patient-Centered Care

The theme *patient-centered care* was related to lower satisfaction with the dental encounter. Initially, this might seem odd because we would expect patient centeredness in dental health care to be a positive element. However, in this case, we would argue that the patients would primarily use words related to this theme when they discuss the lack of patient centeredness, which could again be similar to the notion of unmet expectations. In any case, it is clear that the patients in this study are concerned with patient centeredness in a dental context, which is in support of other findings suggesting that dentists need to improve their communication skills and be empathetic when cooperating with patients [45]. Furthermore, research has shown that dental students' self-reported empathy may diminish with increased patient interaction [46]. Even so, a study investigating a patient-centered training program and its effects on dental students' self-reported empathy has revealed promising results to halt this concerning trend [47]. Other research implementing communication training programs in dentistry show that applying active training methods, such as role play and patient treatment experience, as well as acquiring behavioral or psychological knowledge alongside attending more traditional didactic lectures, was most effective in improving dental students' communication skills [48].

Assurance and Explanation

The theme *assurance* was associated with higher patient satisfaction, supporting results from other studies that have proposed a link between higher patient satisfaction and the perception of caring or comforting staff behavior [21]. This supports the idea that in dental encounters, patients might be in need of assurance and comforting behaviors because they might perceive that they have little control over the situation. The establishment of trust between the dentist and the patient has long been regarded as an essential part of treatment, with a

corresponding impact on treatment outcomes [49]. Therefore, behaviors associated with *assurance* could help prevent a challenging encounter. It has been found too that when patients perceive their dentists' *explanation* skills as good, they indicate greater satisfaction with treatment [50,51]. The relationship among the dental health professionals involved in the treatment seems to influence patient satisfaction [52], as well as the dental assistant's knowledge of the patient's needs [51]. Investing time in careful explanations before and during treatment could be a useful way to prevent challenging encounters and increase patient satisfaction.

Professional Advice

Dentists have a professional responsibility to teach patients how to take care of their oral health. The theme *professional advice* could be interpreted as the patients' perception of this teaching practice. It could also be viewed as proof that patients welcome professional advice regarding how to take care of their oral health. Oral health literacy is the individual's ability to obtain, understand, and use oral health information [53,54]. According to a recent literature review, it consists of three important aspects: (1) the individual's capacity to access health information through basic information acquisition skills (eg, the ability to read, an understanding of numbers, and the capability to interpret facial expressions), (2) the individual's ability to use the information (eg, informed decision-making), and (3) oral health maintenance abilities (eg, self-regulation and goal achievement) [55]. The patient's perception of the dentist's ability to communicate and provide useful information about the patient's oral health is therefore dependent not only upon the skills of the dentist but also on the patient's oral health literacy. Dentists should consider that health information can be difficult to access and that information should be individually adapted according to patients' abilities.

Recommendation, Performance Assessment, and Facilities

Not surprisingly, the patients who wrote about positive dental encounters used more words related to *recommendation*, which suggests a need to disseminate their view of the dentist to peers on the web. Other research has supported the existence of this need, where web-based review sites are used to disseminate experiences and views to peers [20]. This sharing of experiences is believed to have a more profound meaning to users than can sometimes be suspected because shared experiences can function as a gateway to feeling connected to others and feeling empowered as a user of health care services [56]. In addition, *performance assessment* was associated with a higher satisfaction rating. This is supported by previous research findings linking patients' perception of high-quality performance to increased patient satisfaction [21,57]. Dental health professionals could benefit from continuous training in clinical skills and striving to update their knowledge according to medical advances. The theme *facilities* was linked to a small increase in odds that the patient was satisfied, which extends the prior finding that patients seemed to write about clinical facilities in both positive encounters and challenging encounters [26] and that this theme was seemingly independent of the satisfaction rating. However, high-quality facilities have been

linked to higher patient satisfaction in previous studies [21,58]. As some of these studies were conducted with inpatients at hospitals, it could be the case that patients needing to stay longer at the clinic found high-quality facilities to be more important for overall satisfaction.

Strengths and Limitations

A LIWC analysis is best performed when the word count in each sample text exceeds 50 [30]. As previously stated, LIWC dictionaries work by calculating the relative percentage of a word's occurrence in a body of text. In samples with small text sizes, for example 5 to 10 words, the relative percentage of each word tends to be very high; for example, in the sentence "I was at Molly's birthday," we see that the word "birthday" accounts for 20% of the word use. To counteract this effect, Boyd [30] suggests that one could have a sample size that is very large. For dental patients' reviews to be accepted on the previously mentioned Norwegian website, they need to be at least 100 characters long [59]. We would argue that, in this case, since the mean word count is close to 50 (mean 48.9, SD 39) and the sample size is large (n=11,764), our findings will be less affected by this bias. However, it could prove valuable to repeat this study using larger sample sizes. As a language analysis tool, the LIWC has proven to be reliable in research [29], with examples available from a wide range of research to underscore its usefulness [60,61].

In general, it would be expected that only a limited number of patients would write a web-based review after a visit to the dentist. A true estimate of the response rate is not possible because we do not know the exact number of patients who have chosen not to respond or whether a patient has provided ratings for several dentists. Given the low review volume relative to the dentist-to-patient ratio (1:1250 [62]) and a mean of 3.9 reviews per dentist, only a small percentage of patients likely write online reviews. However, this should not significantly impact our ability to investigate themes related to high versus low patient satisfaction, which was our study objective. Because most of the reviews were positive (10,977/11,764, 93.31% have a rating of 4-5 stars), this could mean that the findings in our study are more representative of positive reviews. To counteract this bias, one could consider splitting the data set into 2 parts before analysis: the reviews with a low satisfaction rating (1-2 stars) versus the reviews with a high satisfaction rating (4-5 stars). This approach would enable a separate word analysis for each data set to compare the satisfied patients versus the unsatisfied patients and their word use. However, the number of reviews representing a low satisfaction rating was considered to be insufficient to provide reliable results in a bottom-up text analysis using the MEM, which usually depends on a large amount of text data to provide reliable results.

In the exploratory factor analysis performed using SPSS software, the words within each word category were extracted from the body of text based on how often they appeared together in a phrase. The interpretation and labeling of the themes were based on a theoretical understanding of the meaning of the factors. Other researchers intending to perform similar analyses could arrive at different theme labels based on their particular theoretical understanding; for instance, the theme *consequences of treatment need* was a broad category containing a greater number of words than the other themes, and we found it difficult to interpret and to agree on the final label because it seemed to be a theme with multiple layers. By contrast, other themes containing fewer words were more easily interpretable (eg, the themes *facilities* or *assurance*). This is a limitation related to the use of factor analysis often mentioned in the literature [63]. Despite these challenges, previous research has arrived at themes that are similar in their content with regard to patient satisfaction [21,57], indicating that our findings could be applicable in other contexts.

Implications for Future Research

Websites provide large amounts of text data that will enable researchers to perform large-scale analyses (eg, using text analysis programs that build upon machine learning methods, such as BERT [64]). Even so, machine learning methods could encounter difficulties related to "poor language" in short internet texts, elucidating the need to develop these methods further [65]. The findings from this study and similar studies could help clinicians develop a better understanding of their patients' perspectives and needs in light of challenging treatment situations. Hopefully, some of these findings could also help guide future research on increasing patient satisfaction, while limiting challenging encounters in the dental clinic. In addition, there is a need to establish effective interventions to motivate patients to visit their dentist regularly.

Conclusions

The findings of this study demonstrate the value of web-based patient reviews as a gateway to patient experiences, and we would argue that implementing the themes or elements from the themes expressed in these reviews could help improve patient satisfaction. While dissatisfaction with dental treatment seems to be associated with negative consequences and (a lack of) patient centeredness, high satisfaction seems to hinge on patients' experiences of being acknowledged by the dentist. Investigations of web-based reviews could produce valuable insights into what patients experience and value in dental treatment settings.

Acknowledgments

The authors would like to acknowledge Legelisten.no AS for their contribution of data to this study. The authors would also like to express their gratitude to the administrators of Språksamlingane (The Norwegian Language Collections) at the University of Bergen for providing a complete Norwegian dictionary in which we could find words for our customization of the Linguistic Inquiry and Word Count 2007 Norwegian dictionary. This project was funded as part of the Student Research Program at the Department of Clinical Dentistry, UiT The Arctic University of Norway.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Lemmatization list.

[[TXT File , 25 KB - jopm_v16ile49262_app1.txt](#)]

Multimedia Appendix 2

Stop list.

[[TXT File , 1 KB - jopm_v16ile49262_app2.txt](#)]

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Abbreviations

LIWC: Linguistic Inquiry and Word Count

MEM: meaning extraction method

NLP: natural language processing

OR: odds ratio

VPC: variance partition coefficient

Edited by S Woods; submitted 24.05.23; peer-reviewed by M Elbattah, M Pang, Y Freire, M Sarhan; comments to author 11.10.23; revised version received 15.11.23; accepted 22.03.24; published 03.05.24.

Please cite as:

Larsen M, Holde GE, Johnsen JAK

Investigating Patient Satisfaction Through Web-Based Reviews of Norwegian Dentists: Quantitative Study Using the Meaning Extraction Method

J Particip Med 2024;16:e49262

URL: <https://jopm.jmir.org/2024/1/e49262>

doi: [10.2196/49262](https://doi.org/10.2196/49262)

PMID: [38700933](https://pubmed.ncbi.nlm.nih.gov/38700933/)

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Original Paper

Patients' Perspectives on Plans Generated During Primary Care Visits and Self-Reported Adherence at 3 Months: Data From a Randomized Trial

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Abstract

Background: Effective primary care necessitates follow-up actions by the patient beyond the visit. Prior research suggests room for improvement in patient adherence.

Objective: This study sought to understand patients' views on their primary care visits, the plans generated therein, and their self-reported adherence after 3 months.

Methods: As part of a large multisite cluster randomized pragmatic trial in 3 health care organizations, patients completed 2 surveys—the first within 7 days after the index primary care visit and another 3 months later. For this analysis of secondary outcomes, we combined the results across all study participants to understand patient adherence to care plans. We recorded patient characteristics and survey responses. Cross-tabulation and chi-square statistics were used to examine bivariate associations, adjusting for multiple comparisons when appropriate. We used multivariable logistic regression to assess how patients' intention to follow, agreement, and understanding of their plans impacted their plan adherence, allowing for differences in individual characteristics. Qualitative content analysis was conducted to characterize the patient's self-reported plans and reasons for adhering (or not) to the plan 3 months later.

Results: Of 2555 patients, most selected the top box option (9=definitely agree) that they felt they had a clear plan (n=2011, 78%), agreed with the plan (n=2049, 80%), and intended to follow the plan (n=2108, 83%) discussed with their provider at the primary care visit. The most common elements of the plans reported included reference to exercise (n=359, 14.1%), testing

(laboratory, imaging, etc; $n=328$, 12.8%), diet ($n=296$, 11.6%), and initiation or adjustment of medications; ($n=284$, 11.1%). Patients who strongly agreed that they had a clear plan, agreed with the plan, and intended to follow the plan were all more likely to report plan completion 3 months later ($P<.001$) than those providing less positive ratings. Patients who reported plans related to following up with the primary care provider ($P=.008$) to initiate or adjust medications ($P\leq.001$) and to have a specialist visit were more likely to report that they had completely followed the plan ($P=.003$). Adjusting for demographic variables, patients who indicated intent to follow their plan were more likely to follow-through 3 months later ($P<.001$). Patients' reasons for completely following the plan were mainly that the plan was clear ($n=1114$, 69.5%), consistent with what mattered ($n=1060$, 66.1%), and they were determined to carry through with the plan ($n=887$, 53.3%). The most common reasons for *not* following the plan were lack of time ($n=217$, 22.8%), having decided to try a different approach ($n=105$, 11%), and the COVID-19 pandemic impacted the plan ($n=105$, 11%).

Conclusions: Patients' initial assessment of their plan as clear, their agreement with the plan, and their initial willingness to follow the plan were all strongly related to their self-reported completion of the plan 3 months later. Patients whose plans involved lifestyle changes were less likely to report that they had "completely" followed their plan.

Trial Registration: ClinicalTrials.gov NCT03385512; <https://clinicaltrials.gov/study/NCT03385512>

International Registered Report Identifier (IRRID): RR2-10.2196/30431

(*J Particip Med* 2024;16:e50242) doi:[10.2196/50242](https://doi.org/10.2196/50242)

KEYWORDS

primary care; survey; patient adherence; adherence; self-reported; surveys; content analysis; RCT; randomized; controlled trial; controlled trials; plan; plans; willingness; experience; experiences; attitude; attitudes; opinion; opinion; perception; perceptions; perspective; perspectives

Introduction

Primary care is an essential component of health care in the United States, where primary care providers (PCPs) provide comprehensive and longitudinal care to patients [1]. The role of the PCP has expanded over time, with PCPs providing more diagnoses, more treatments, and more preventive services in recent years [2]. In 2015, about 25% of PCP visits were for preventive care, about 30% care for chronic conditions, and just under 40% for acute care [3]. In many instances, primary care visits generate a plan for follow-up actions that extend beyond the encounter, as care often involves tasks that the patient (and sometimes the PCP) will do in the subsequent days and weeks. Ideally, the patient and the PCP jointly decide upon and agree to a plan [4], which might involve initiating or adjusting medications, monitoring symptoms, scheduling tests, implementing lifestyle modifications, or a multitude of other steps. Adherence to plans is affected by a broad range of factors including the provider-patient relationship [5]. One meta-analysis reported a 19% greater risk of nonadherence among patients who reported their physician communicated poorly during the visit [6].

While there is a substantial body of research on patient adherence, much of it is focused on adherence in the context of specific diseases, such as diabetes [7], coronary heart disease [8], asthma [9], and depression [10]. Medication adherence has been particularly well studied; 1 meta-analysis of 50 years of adherence research found that 63% of the studies focused on medication adherence, with many fewer studies examining adherence to recommendations for changes in diet (4.8%) and exercise (2.5%) [11]. In general, overall adherence rates have been estimated to range between 50% and 75%, suggesting substantial room for improvement [11,12]. Understanding patients' perspectives on the plan that they have (or have not) understood and agreed to and their reasons for following or not

following the plan could provide insights that would help PCPs promote better adherence. To our knowledge, there have been no large, multisite studies in the United States describing patients' perceptions of the plans that result from their primary care visits, the extent to which patients follow these plans, and their reasons for following or not.

The purpose of this study was to describe patients' perceptions of the plans generated during primary care visits and characterize these plans. We also sought to describe patients' reports of whether they adhered to the plan, the extent to which follow-through was related to their initial perceptions of the plan, and their reasons for adherence (or lack of adherence) to the plan.

Methods

Overview

The data for this analysis were collected in the context of a large multisite cluster randomized controlled trial (ClinicalTrials.gov NCT123456) evaluating the impact of 3 approaches to facilitating communication and shared decision-making in primary care encounters. The 3 approaches were 1. in-person coaching for clinicians along with patients receiving a pre-visit questionnaire in advance of their visit regarding what they wanted to talk about and a video about how to prepare for their visit; 2. Mobile app coaching for clinicians and the same 2 components for patients (pre-visit questionnaire and video), and 3. Poster in exam room to encourage shared decision making. The primary study outcomes were patient-reported perceptions of communication and decision making during the appointment. While not one of the primary outcomes, this analysis was of secondary outcomes that were a part of the original research questions to examine patient plans and how patients were then able to carry them out. A detailed description of the methods and the findings of the trial are available elsewhere [13]; we

briefly summarize the relevant methods here. Because the main analysis did not detect a statistically significant difference between the 3 study arms, we do not present the findings about plans by study arm. Additionally, when coding the data, we did not see any major differences across the arms and so we are examining data across all study participants.

English-speaking adult patients with a web-based patient portal account were invited to participate in the study at least 3 days in advance of scheduled appointments with participating PCPs at each site. We selected English-speaking primary care patients as that was the group studied in the initial pilot [14]. We also selected patients with a web-based patient portal account because 2 key components of the intervention (the single-item previsit questionnaire and video) were delivered via the portal. Details about the recruitment processes, which include patient portal and email invitations, have been described elsewhere [15]. Patients who provided informed consent and completed a web-based postvisit survey within 7 days of the visit were sent a follow-up survey approximately 3 months later (also on the web). Nonrespondents to the follow-up survey were sent 2 reminder emails. Patients received a US \$20 incentive for completing each survey. Survey data were collected and managed using REDCap (Research electronic data capture; Vanderbilt University) tools [16,17]. Data collection occurred from September 2019 through November 2021.

The analytic sample for the study reported here includes all patients who completed the initial postvisit survey within 7 days of the visit and also completed a 3-month survey. We focus specifically on the questions related to development and adherence to plans generated during the visit. In the initial postvisit survey, patients' perceptions of the plan discussed during their medical appointment were assessed with 3 statements, each rated on a 10-point scale (from 0 to 9, with 0 as "strongly disagree" and 9 as "strongly agree"): (1) My doctor and I have a clear plan for what to do next about my health issues; (2) I agree with the plan my doctor and I have for taking care of my health issues; and (3) I will follow the plan my doctor and I made for taking care of my health issues. Patients were asked to enter a free-text response to the open-ended question: "Thinking about the plan that you and your doctor made, what is the most important thing that you will do over the next three months?"

In the 3-month survey, patients' descriptions of their plan from the postvisit survey (ie, response to "the most important thing you will do") were populated into the survey to remind patients of what they had written originally. Patients were then asked: "To what extent have you carried out the plan?" with response options of "Completely," "Somewhat," "Not At All," and "This Doesn't Apply To Me/I Didn't Have a Plan." Patients who responded "Somewhat" or "Not At All" were asked to select from a list of reasons for not carrying out the plan and those who responded "Completely" were asked to select what helped them adhere to the plan. Patients were able to select multiple reason options or write in a text response.

Ethical Considerations

The study was conducted at 3 health care organizations in 2 states (California and Massachusetts). The overall study,

including these secondary outcomes, was reviewed and approved by institutional review boards at Sutter Health (2017.094EXP), the University of California San Diego (#180310), and the UMass Chan Medical School (H0001310).

Analysis

We computed means and frequencies to describe the patient characteristics and responses to the survey questions described above. We dichotomized patients' responses to each of the 3 questions about communication into the "top box," indicating whether the patient gave the highest score possible, that is, 9 or less than top box. This approach is often used operationally [14]. Cross-tabulation and chi-square statistics were used to examine the bivariate associations between patients' initial postvisit ratings of their plan and reported plan adherence approximately 3 months later. We also examined the association between the type of plan and plan adherence. We also examined the association between the type of plan and plan adherence. Significance values were adjusted by the Bonferroni corrections for multiple comparisons for the various types of plans. The binary outcome of carrying out the plan was analyzed using a multipredictor logistic regression, including the 3 questionnaire responses mentioned above and adjusted for the demographic factors to demonstrate how the patients' understanding or agreement or intention to follow the plan impacts the adherence to the plan, allowing for differences due to various characteristics. We used qualitative content analysis to categorize responses to the open-ended questions "Thinking about the plan that you and your doctor made, what is the most important thing that you will do over the next three months?" in the postvisit survey and the free-text responses to other reasons for not adhering to a plan and adhering to a plan in the 3-month survey.

We developed a codebook for the content analysis using an iterative process. Investigators and staff at each site first reviewed the free-text responses for their site to create inductive codes capturing the content evident in the responses. We then compared the codes generated at each site to determine common codes and established a formal codebook that coders at each site applied to their data. Coders flagged any text that was difficult to code and brought these responses to the full coding team, which discussed the text and determined whether modifications to the coding scheme were needed. The full coding team also adjudicated final code assignments for any difficult or questionable responses.

Results

We present the results combining all 3 sites as we found that they were very similar during the qualitative analysis. The analytic sample for this study included 2555 patients who completed both the postvisit and 3-month surveys (3847 total completed surveys, 66.4%). Patient participants were on average 52 (SD 16.4) years old. The majority were female (n=1662, 65%), White (n=2097, 82%), non-Hispanic (n=2304, 90%), and had a 4-year college degree or higher (n=1151, 72%). Many (n=1547, 60.5%) had their visit during the COVID-19 pandemic (eg, after March 16, 2020; Table 1).

Overall, a large majority of patients selected the top box option (9=definitely agree) to indicate that they felt they had a clear plan (n=2011, 78%), agreed with the plan (n=2049, 80%), and intended to follow the plan (n=2108, 83%) discussed with their PCP.

The types of plans patients reported are summarized in [Table 1](#). Patients could report more than 1 type of plan or a plan that included multiple components. The most common elements of the plans reported included reference to exercise (n=359, 14.1%), testing (laboratory, imaging, etc; n=328, 12.8%), diet (n=296, 11.6%), and initiation or adjustment of medications (n=284, 11.1%). The correspondence between patients' views of their plan as reported soon after the visit and their report of whether they had followed the plan 3 months later is presented in [Table 2](#). Patients who reported that they had a clear plan, agreed with the plan, and intended to follow the plan were all more likely to report completion of the plan 3 months later compared to those who provided less positive ratings on these items initially ($P<.001$). [Table 2](#) also shows the percentage of patients who reported they had "Completely" followed through 3 months later for each type of plan. Patient plans related to following up with the PCP, initiating or adjusting medications, and having a specialist visit were more likely to indicate that

they had completely followed the plan ($P=.008$, $P\leq.001$, and $P=.003$, respectively). Patients whose plans involved lifestyle changes such as weight loss, diet, and exercise were less likely to report that they had "Completely" followed their plan than those whose plans did not involve lifestyle changes ($P<.001$).

For the multivariable logistic regression, compared to those who responded other than "definitely agree," those patients who indicated "definitely agree" that they would follow the plan were more likely to report 3 months later that they completely followed the plan (adjusted odds ratio 1.95, 95% CI 1.48-2.58; [Table 3](#)).

Patients were able to report more than 1 reason for following or not following the plan. Patients' reasons for completely following the plan included that the plan was clear (n=1114, 69.5%), consistent with what mattered (n=1060, 66.1%), they were determined to carry through with the plan (n=887, 53.3%), and had the support needed to carry through the plan (n=570, 33.7%; [Table 4](#)). The most common reasons for *not* following the plan were lack of time (n=217, 22.8%), decided to try a different approach (n=105, 11%), the COVID-19 pandemic impacted the plan (n=105, 11%), the plan did not fit the lifestyle (n=93, 9.7%), and the plan was no longer needed or relevant (n=90, 9.5%; [Table 4](#)).

Table 1. Sample characteristics (N=2555).

Characteristic	Overall sample
Age (years)	
Median (IQR)	54.0 (39.0-66.0)
mean (SD)	52.6 (16.4)
Gender, n (%)	
Female	1662 (65)
Male	838 (32.8)
Other or missing	55 (2.15)
Race, n (%)	
American Indian or Alaska Native	12 (0.5)
Asian	266 (10.4)
Black or African American	50 (2)
Native Hawaiian or other Pacific Islander	11 (0.4)
White	2097 (82.1)
More than 1 race	68 (2.7)
Missing	51 (2)
Ethnicity, n (%)	
Hispanic	231 (9)
Non-Hispanic	2304 (90.2)
Missing	20 (0.8)
Education, n (%)	
High school graduate or general educational diploma or less	161 (6.3)
Some college or 2-year degree	548 (21.4)
4-year college graduate	695 (27.2)
More than a 4-year college degree	1151 (45)
Index visit on or after March 16, 2020 (COVID-19 pandemic), n (%)	
No	986 (38.6)
Yes	1547 (60.5)
Missing	22 (0.9)
Health system, n (%)	
A	1240 (48.5)
B	857 (33.5)
C	458 (17.9)
How confident are you in filling out forms by yourself?, n (%)	
Extremely	2309 (90.4)
Quite a bit or somewhat or a little bit	237 (9.3)
Not at all	7 (0.3)
Missing	2 (0.1)
Type of plan, n (%)^a	
Exercise	359 (14.1)
Testing (laboratory, imaging, etc)	328 (12.8)
Diet	296 (11.6)
Medication management	284 (11.1)

Characteristic	Overall sample
Specialist referral	246 (9.6)
Monitor or control condition	218 (8.5)
Follow-up with PCP ^b	181 (7.1)
Lose weight	96 (3.8)
Other strategies not specified above ^c	230 (9)
Other preventive behaviors not specified above ^d	168 (6.6)
Did not have a plan	17 (0.7)
My doctor and I have a clear plan for what to do next about my health issues, n (%)	
Definitely agree ("top box")	2011 (78.7)
Less than definitely agree	544 (21.3)
I agree with the plan my doctor and I have for taking care of my health issues, n (%)	
Definitely agree ("top box")	2049 (80.2)
Less than definitely agree	506 (19.8)
I will follow the plan my doctor and I made for taking care of my health issues, n (%)	
Definitely agree ("top box")	2108 (82.5)
Less than definitely agree	447 (17.5)
To what extent have you carried out the plan?, n (%)	
Completely	1603 (62.7)
Not at all or somewhat	952 (37.3)

^aPlans could include more than 1 component; categories are not mutually exclusive.

^bPCP: primary care provider.

^cOther strategies included physical therapist, occupational therapist, health educator, mental health therapy, herbal supplements, managing stress, and independent learning.

^dSmoking cessation, vaccination, reducing alcohol consumption, and general comments about healthy lifestyle.

Table 2. Extent of the followed plan by intention and types of plan.

Characteristics	To what extent have you carried out the plan?		Odds ratio (95% CI)	Overall <i>P</i> value
	Completely (n=1603, 62.7%), n (%)	Less than completely (n=952, 37.3%), n (%)		
My doctor and I have a clear plan for what to do next about my health issues				<.001
Definitely agree (“top box”)	1323 (65.8)	688 (34.2)	1.81 (1.5-2.2)	
Less than definitely agree	280 (51.5)	264 (48.5)	N/A ^a	
I agree with the plan my doctor and I have for taking care of my health issues				<.001
Definitely agree (“top box”)	1350 (65.9)	699 (34.1)	1.93 (1.59-2.35)	
Less than definitely agree	253 (50)	253 (50)	N/A	
I will follow the plan my doctor and I made for taking care of my health issues				<.001
Definitely agree (“top box”)	1398 (66.3)	710 (33.7)	2.32 (1.89-2.86)	
Less than definitely agree	205 (45.9)	242 (54.1)	N/A	
Types of plan				
Exercise	174 (48.5)	185 (51.5)	0.51 (0.37-0.7) ^b	<.001 ^c
Testing (laboratory, imaging, etc)	222 (67.7)	106 (32.3)	1.28 (0.9-1.84) ^b	.54 ^c
Diet	149 (50.3)	147 (49.7)	0.56 (0.4-0.8) ^b	<.001 ^c
Medication management	209 (73.6)	75 (26.4)	1.75 (1.19-2.63) ^b	<.001 ^c
Specialist referral	181 (73.6)	65 (26.4)	1.73 (1.15-2.68) ^b	.003 ^c
Monitor or control condition	152 (69.7)	66 (30.3)	1.4 (0.92-2.19) ^b	.31 ^c
Follow-up with primary care provider	135 (74.6)	46 (25.4)	1.81 (1.12-3.02) ^b	.008 ^c
Lose weight	41 (42.7)	55 (57.3)	0.43 (0.23-0.77) ^b	<.001 ^c
Other strategies not specified above	127 (55.2)	103 (44.8)	0.71 (0.48-1.05) ^b	.16 ^c
Other preventive behaviors not specified above	100 (59.5)	68 (40.5)	0.86 (0.55-1.38) ^b	≥.99 ^c

^aN/A: not available.

^bBonferroni-corrected 99.5% CI.

^cBonferroni-corrected *P* value.

Table 3. Adjusted logistic regression of extent followed plan.

Explanatory variable	Odds ratio (95% CI)	Overall P value
My doctor and I have a clear plan for what to do next about my health issues: Definitely agree (“top box”; Reference: Less than definitely agree)	1.16 (0.85-1.57)	.35
I agree with the plan my doctor and I have for taking care of my health issues: Definitely agree (“top box”; Reference: Less than definitely agree)	1.15 (0.82-1.60)	.42
I will follow the plan my doctor and I made for taking care of my health issues: Definitely Agree (“top box”; Reference: Less than definitely agree)	1.95 (1.48-2.58)	<.001
Age	1.0 (1.0-1.0)	.80
Gender: non-female or missing (Reference: Female)	1.03 (0.87-1.23)	.71
Race: non-White (Reference: White)	1.10 (0.87-1.39)	.43
Education: less than a 4-year college degree (Reference: 4-year college graduate)	0.92 (0.76-1.11)	.39
Index visit on or after March 16, 2020: Yes (Reference: No)	1.05 (0.88-1.25)	.60
Health system (Reference: A)		
B	0.93 (0.77-1.13)	.46
C	0.81 (0.64-1.02)	.07

Table 4. Reasons for following the plan.

	Values, n (%)
Patients who reported “Completely” followed the plan (n=1603)	
What helped you to carry out the plan? (Select ALL that apply)	
The plan was clear to me	1114 (69.5)
The plan was consistent with what mattered most to me	1060 (66.1)
I was determined to carry it through	887 (55.3)
I had the support needed to carry it through	540 (33.7)
Other	19 (1)
Patients who reported “Not at All” or “Somewhat” followed plan (n=952)	
There are many reasons why people do not carry out a plan exactly. Please select ALL reasons that apply to you	
5 most frequently selected responses	
Lack of time	217 (22.8)
Try a different approach	105 (11)
Did not fit with my lifestyle	93 (10)
Plan was no longer needed or relevant	90 (9)
Plan was not working	39 (4)
5 most frequently written in as “Other”	
Impact from COVID-19	105 (11)
Plan in progress	77 (8)
Life events or activities of daily living impact	44 (5)
Not motivated to complete the plan	40 (4.2)
Other health issues	33 (3)

Discussion

Principal Findings and Comparison With Prior Work

In this multisite study of primary care visits, we found that the majority (roughly 80%, n=2049 and 2108, respectively) of patient participants felt that they agreed with and would follow the plan that resulted from their primary care visit. These views gathered soon after their PCP visit were statistically significantly associated with the likelihood of completely following their plan after controlling for other factors. Patients who did not feel clear about the plan or who were not in agreement with the plan were much less likely to follow the plan. This is consistent with the finding reported in 1 meta-analysis, which found that the odds of patient adherence are 2.16 times higher if a physician communicates effectively [6]. This suggests that future studies could evaluate whether providers could improve treatment adherence through “teach-back,” where they confirm patients understand and are in agreement with the plan before the end of the visit [18].

We found that many patients reported that they did not completely follow plans related to weight loss, diet improvement, and increased exercise. These findings are consistent with other studies that found patients tended to be more adherent to circumscribed treatment regimens (eg, medication use) as compared to complex health behavior change efforts such as diet [11]. Given these challenges and limited insights provided through research, patients and providers may need to be proactive and anticipate difficulties in these areas. The evidence suggests that “knowledge alone is not sufficient to enhance adherence in recommendations involving complex behavior change” [19] like modifying diet and exercise. Providers should consider simplifying proposed regimen changes to better “match patients’ activities of daily living” [19]. Motivational interviewing could be used to better help the patient identify and set their own goals and identify both potential barriers and ways to overcome them [20]. Some other potential ways to improve provider communication include additional training on how to provide empathy [21] as empathy has been shown to improve both adherence and patient satisfaction [22,23] and training on agenda setting can help the flow of the visit and improve the overall interaction [24].

Many patients in our study identified lack of time as the reason for not fully adhering to their plan, which is also consistent with

previous research [25]. Patients in our study were further impacted by the COVID-19 pandemic, which caused nonessential medical appointments to be canceled, affecting patients’ plans to follow up with their PCPs or specialists, or to complete laboratory testing. Gyms were closed, which impacted some patients’ plans to exercise. Other researchers have documented the impact of COVID-19 on exercise in the general population; for instance, a survey conducted in November 2020 found that over 25% of respondents said that they still did not go out to walk, hike, or exercise even after the initial pandemic lockdown restrictions were lifted [26].

Limitations

A major limitation of our study is our reliance on patient self-report. Participating patients may have only reported limited descriptions of their plans, whereas there may have been more in-depth discussions with their PCP about the plans and next steps during the actual conversations. We also did not provide an opportunity for patients to identify elements of their physician’s recommendations, and future research should consider potentially incorporating this aspect. We did not capture the PCP’s perspective on the encounter or the plan, and doing so would have allowed us to examine the correspondence between the patient’s understanding of the plan and the PCP’s understanding of what had been agreed to (or what was most important). Our analysis assumed that all patient plans carried equal clinical importance and we did not evaluate for complexity of the plan. These are 2 factors that could potentially impact plan adherence. Additionally, our population was predominately White and nearly half have more than a 4-year college degree; their ability to understand instructions and reasoning to carry out the plan may not be representative of what might be found in a general population. Finally, our study evaluated plan adherence after 3 months so that may be insufficient time to expect resolution of some more complex medical issues.

Conclusions

In this multisite study of patients’ views on their primary care visits and the plans generated during these visits, we found that overall, patients’ initial assessment of their plan as clear, their agreement with the plan, and their initial willingness to follow the plan were all strongly related to their self-reported completion of the plan 3 months later.

Acknowledgments

The research reported in this paper was funded through a Patient-Centered Outcomes Research Institute (PCORI) award (contract IHS-1608-35689-IC). The views in this paper are solely the responsibility of the authors and do not necessarily represent the views of the PCORI, its Board of Governors, or the Methodology Committee.

Conflicts of Interest

None declared.

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Abbreviations

PCP: primary care provider

REDCap: Research Electronic Data Capture

Edited by M Hudson; submitted 15.08.23; peer-reviewed by W Bensken, M Ma; comments to author 08.09.23; revised version received 02.11.23; accepted 12.11.23; published 14.03.24.

Please cite as:

Stults CD, Mazor KM, Cheung M, Ruo B, Li M, Walker A, Saphirak C, Vaida F, Singh S, Fisher KA, Rosen R, Yood R, Garber L, Longhurst C, Kallenberg G, Yu E, Chan A, Millen M, Tai-Seale M

Patients' Perspectives on Plans Generated During Primary Care Visits and Self-Reported Adherence at 3 Months: Data From a Randomized Trial

J Particip Med 2024;16:e50242

URL: <https://jopm.jmir.org/2024/1/e50242>

doi: [10.2196/50242](https://doi.org/10.2196/50242)

PMID: [38483458](https://pubmed.ncbi.nlm.nih.gov/38483458/)

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JMIR Publications
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