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ORIGINAL ARTICLE

ShareHeart: A patient journey map of patients with ischemia and non-obstructive coronary artery disease based on qualitative research

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Abstract

Aims and objectives: To visualise the health care experiences and needs of patients with ischemia with non-obstructive coronary arteries in a patient journey map. As such, future design challenges can be provided, and it can be used for future health-care optimization.

Background: Ischemia with non-obstructive coronary arteries is a chronic cardiac condition caused by vascular dysfunctions. Ischemia with non-obstructive coronary arteries is often unrecognised, significantly impairs daily functioning, and is more prevalent among women. Patients' experiences remain unexplored, and a clear patient-centered care pathway is lacking.

Design: A qualitative interpretative research design was performed and the standards for reporting qualitative research (SRQR) has been used.

Methods: In total, 36 women were included and participated in eight semi-structured focus group interviews. Thematic analysis was used, and identified themes were further classified using 'patient journey mapping.' Additionally, Picker's 'eight principles of patient-centered care' were linked to the results and integrated in the patient journey map.

Results: Participants experienced a lack of familiarity with the specific cardiac condition by healthcare providers, repeated hospitalisation, testing and referrals, shortage of specialised cardiologists, and feelings of not being heard. In addition, needs for a multidisciplinary treatment program (including physical and psychological support), better information provision, and an easily accessible contact person were expressed.

Conclusions: The resulting patient journey map shows how patients experienced and interacted with the current healthcare system. Overall, the results show a complex and long healthcare pathway and important themes for healthcare experiences and needs were identified. Future research could focus on the development and

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implementation of a patient-centered evidence-based clinical pathway optimising experiences and quality of life.

Relevance to clinical practice: The visual tool can help health care professionals, policy makers, and researchers improve healthcare provision which is patient-centered and tailored to the preferences of patients with ischemia with non-obstructive coronary arteries.

KEYWORDS
health care quality improvement, ischemia with non-obstructive coronary arteries (INOCA), patient centered care, patient journey map, patients experiences, qualitative study

1 | INTRODUCTION

Ischemia with non-obstructive coronary arteries (INOCA) is an ischemic heart disease predominantly seen in women and caused by coronary vascular dysfunctions including epicardial or microvascular coronary vasospasm and/or microvascular dysfunction encompassing diminished coronary flow reserve and/or increased microvascular resistance (Beltrame et al., 2017; Ong et al., 2018). Up to two-thirds of symptomatic patients without significant obstructive coronary arteries have INOCA (Anderson et al., 2019; Jaskanwal et al., 2015). Patients with INOCA have recurrent cardiac symptoms, elevated risks for adverse cardiac events, repeated invasive and non-invasive tests, higher rates of rehospitalizations, and an impaired quality of life (QoL) (Jespersen et al., 2012, 2013, 2014). Despite increasing knowledge of INOCA, patients' experiences remained unexplored, and a clear patient-centered care pathway is lacking. As a first step to healthcare quality optimization, this focus group study aims to visualise patients' healthcare pathway (journey) by exploring their experiences and healthcare needs.

Patient Centered Care (PCC) is defined as "providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions" (Institute of Medicine, (US) Committee on Quality of Health Care in America, 2001). PCC benefits patients' health outcomes, satisfaction, and is related to fewer diagnostic tests and referrals (Olsson et al., 2012; Stewart et al., 2000). According to the Picker institute, PCC consist of eight important elements: access to care, continuity and transition, involvement of family and friends, emotional support, physical comfort, information and education, effective and trusted treatment, and respect for patients' preferences (Figure S1). To integrate these core principles into a clear care pathway it is important to first investigate INOCA patients' experiences during their current healthcare journey.

Currently, the INOCA care pathway encompasses different challenges for both patients and healthcare providers. First, symptom presentations are difficult to discriminate from other cardiac and non-cardiac diseases (Konst et al., 2020; Kunadian et al., 2020). Second, recent definitions and diagnosis protocols (Elias-Smale et al., 2020; Knuuti et al., 2020) have not been widely implemented. Third, routine diagnostic tests such as a coronary angiogram are insensitive to detect coronary vascular dysfunctions, overlooking diagnoses of treatable patients (Ford & Berry, 2019). Finally, existing specific invasive coronary function tests are limited available in hospitals, are seldom performed, and not without risks (Ford & Berry, 2019; Konst et al., 2020). With this in mind, it can be stated that the care pathway is fragmented. Consequently, patients with INOCA remain underdiagnosed and undertreated and often have a diagnostic and adequate treatment delay of several years (Herscovici et al., 2018).

Recent evidence, focusing on diagnostics, suggest the need for further implementation of PCC to improve healthcare experiences and QoL in INOCA patients. Williams et al. (2017) demonstrated that standard cardiac diagnostic testing was associated with deterioration in symptoms and QoL in patients with non-obstructive coronary artery disease. Explanations were no justification for their symptoms, false reassurance, and discontinuation of medical therapy. Moreover, the Coronary Microvascular Angina (CorMicA) trial has highlighted that stratified medicine improves symptom experience and QoL for the short and long term as compared to care as usual (Ford et al., 2018, 2020).

No previous study has investigated INOCA patients' experiences during the entire healthcare pathway. Exploring the experiences and needs helps to understand how patients perceive provided care and why and when it is experienced positively or negatively, and to identify challenges in their health care process. It may subsequently generate solutions to solve challenges and aids to implement a patient-centered care pathway. A patient-centered care pathway leads to better coordinated and less fragmented care where the

What does this paper contribute to the wider global clinical community?

- This study gives insight and creates awareness on the current health care pain points (dilemmas), needs, and experiences of patients with ischemia but non-obstructive coronary arteries
- Essential design challenges are provided to support health care professionals, researchers, and policy makers in improving and implementing a patient-centered health care pathway tailored to the preferences and values of the patient

needs and values of patients are integrated. It helps to standardise clinical activities so that provided care becomes more consistent and efficient while still being patient-centered. This could improve patients' outcomes and quality of life and may contribute to reduced health care costs (Olsson et al., 2012).

Therefore, in the present focus group study, we aim to create a patient journey map by exploring the experiences and health care needs. Using a patient journey map, problems can be identified and suggestions for improvements and opportunities (*design challenges*) will be made. The resulting tool can be used as a starting point to improve to quality and efficacy of the healthcare pathway towards a more patient-centered care system for patients with INOCA.

2 | METHODS

2.1 | Study design

The ShareHeart study explores the experiences and needs of both patients and health care providers (HCPs) using an interpretative qualitative design. Standards for reporting qualitative research (SRQR) were used (O'Brien et al., 2014) (Appendix S2). Results regarding the experiences of HCPs will be reported separately.

Focus groups were led by the first author (DLS) who is experienced with patient interviews and consultation in the field of cardiology. Prior to the focus group there was no personal involvement with the participants. Two experts (BO & JS) in qualitative research were available for consultation.

2.2 | Population and sampling

Inclusion took place between February 2020 and November 2020 at the Elisabeth-Tweesteden Hospital (ETZ) (Tilburg, Netherlands) and additionally at Radboud university medical center (Nijmegen, Netherlands). Extended inclusion was feasible as focus groups were required to take place online due to COVID-19. The additional data sources contributed to a more geographically dispersed sample enhancing trustworthiness and generalizability.

Purposive sampling was used to include participants who are believed to give the richest answer to the research questions, due to their extensive experience with the health care process (Howitt, 2016). Inclusion criteria were women who were diagnosed with definite INOCA ($N = 14$), based on specific coronary function testing, or suspected for INOCA ($N = 22$), based on signs and symptoms of ischemia without *current* obstructive CAD, and who were seen by a cardiologist specialised in INOCA (Kunadian et al., 2020). Patients who had *current* obstructive CAD were excluded, however, patients with a previous history of (obstructive) CAD were not. Given the higher prevalence of INOCA in women, no men were included. Sampling stopped when data saturation was accomplished (Howitt, 2016). Data saturation was reached when no new information emerged based on field notes and focus group debriefing.

In total, 71 patients were approached of whom 36 participated (ETZ $N = 22$; Radboudumc $N = 14$), 25 declined, five were not available on given dates, three cancelled scheduled interviews, and two did not meet the inclusion criteria. Reasons to decline participation were personal circumstances and the online group setting.

2.3 | Procedure

Participants consented to be contacted by the executive researcher. Next, a patient information form (PIF) was sent by email. Two weeks later, patients were contacted by phone and were invited to participate. Preceding the interviews, a short questionnaire was administered using Qualtrics software (https://www.qualtrics.com), asking about demographics, symptoms, medication use, diagnostics-, and cardiac history.

2.3.1 | Focus groups

Before COVID-19 lockdown in March 2020, one focus group of seven participants took place physically. Afterward, focus groups were shifted to an online setting using Microsoft Teams. User instructions for Microsoft Teams were provided, and when necessary, a practice call was made.

Two-hour semi structured focus groups were executed to explore the experiences and needs of INOCA patients. Small homogenous groups of 4–6 patients were created to optimise conversational interaction between respondents in an online setting. The results of the online focus groups were not expected to differ from face-to-face focus groups (Stewart & Shamdasani, 2017). An interview guideline was used which is provided in the Table S1. The group meeting started with open-ended questions inviting participants to provide brief description of their symptoms and continued with more specific questions regarding the received health care, experiences, diagnostics, treatments, decision moments, and healthcare needs. For verbatim transcription, all groups discussion were audio recorded.

2.4 | Ethical considerations

The study was approved by the institutional Ethic Review Board (ERB) of Tilburg University (RP19), ETZ hospital (METC-Brabant), and Radboudumc (CMO-Radboudumc). All participants gave online informed consent and an oral approval to audio record the discussion. Research assistants (RAs) who supported the data processing signed a nondisclosure agreement.

2.5 | Data analysis

Analysis started in May 2020 and were executed in distinct phases using a computer-assisted software Atlas.ti 8 (ATLAS.ti Scientific Software Development GmbH).

After verbatim transcription, interviews were in a first phase coded according to a thematic analysis research approach which is mainly based on a constructivist research paradigm (Braun & Clarke, 2006). Thematic analysis consists of six interactive phases: familiarising with the data, generating initial codes, searching for themes, reviewing themes, defining, and naming themes, producing the report. In addition to the standard interactive phases, an intermediate step of the creation of a structured code scheme was integrated (Friese, 2019). Three transcripts were independently and inductively coded by DLS and two RAs (with Atlas.ti skills). To create a code scheme, initial codes (e.g., anxiety, knowledge doctor, denial doctor, physical symptoms) and themes were discussed in weekly meetings. Then, the allocated codes in the first three interviews were deleted and all interviews were (re)coded with the code scheme. New added codes were discussed during meetings to guarantee consensus. Phase one resulted in a list of identified common themes. To further classify and effectively visualise the themes it was decided to use the methods of process- and patient journey mapping in a following second phase.

Within the second phase, process mapping was used to outline the healthcare process by plotting described steps and actions (touchpoints) (Antonacci et al., 2018). Next, a patient journey map was created combining the process map and the analysed themes in the first phase. Patient journey maps are being used for patient-centered design approach for designing healthcare solutions taking into account existing constraints (*pain points*) and patient experiences (McCarthy et al., 2016). The resulting visual tool provides insight in how patients experienced and interacted with the current healthcare pathway and helps implementing quality improvements.

To enhance trustworthiness of the study, the process and patient journey maps were shared during two member-check discussions ($N = 14$), and with WMGW (cardiologist) and MHM (nurse practitioner). Summaries of the discussions has been translated and added to the supplementary file (Appendix S1).

The identified themes within phase one, unexpectedly corresponded with Pickers' eight principles of patient centered care (PCC) (Gerteis et al., 1993). Therefore, in a third phase, this framework was integrated into the patient journey map to highlight which principles need improvement according to the patients' view. In addition, it supports our aim to formulate design challenges for future quality improvements and implementation research studies. This may support implementation steps towards a patient-centered care pathway which is based on an evidence-based framework. Founded themes will be linked to and discussed in light of these principles in the discussion section.

3 | RESULTS

3.1 | Sociodemographic and medical background

Sociodemographic and medical backgrounds are presented in Table 1. The sample ($N = 36$) had a mean age of 57.8 (SD = 8.2, median (IQR) = 46.5 (10.8)). Having a cardiac history, was reported in 67% ($N = 24$) of the participants. The sample consisted mainly of middle- to higher-educated participants and most worked part-time (36%, $N = 13$), were incapacitated for work or on disability leave (28%, $N = 10$), or were unemployed/retired (25%, $N = 9$). On average, patients received a diagnosis 4 years after symptom onset (SD = 5.0, median (IQR) = 2.0 (3.0)).

TABLE 1 Demographic and medical characteristics

Characteristics	% (N) or mean (SD)
Sociodemographics	
Age [years]	57.8 (8.2)
Min/Max age	41–75
Education	
High	47% (17)
Middle	47% (17)
Low	6% (2)
Marital status. Living with partner	89% (32)
Work status	
Fulltime employed	11% (4)
Part-time employed	36% (13)
Unemployed/retired	25% (9)
Occupational disability[a]	28% (10)
Medical information	
Treating hospital	
Elisabeth-Tweesteden	60% (22)
Radboudumc	40% (14)
Years till diagnosis	4.1 (5.1)
Min/Max time	0.2–23
Received coronary function test[b]	55% (20)
Cardiac history	67% (24)
History of Myocardial infarction	14% (5)
History of NSTEMI	3% (1)
History of PCI	11% (4)
History of Heart failure	8% (3)
Other history[c]	39% (14)

Abbreviations: MI, myocardial infarction; NSTEMI, non-ST segment elevation myocardial infarction; PCI, percutaneous coronary intervention.

[a]Patients who are fully or partially incapacitated for work, or in a reintegration process, or on sick leave.

[b]Coronary angiography using the Index of Microcirculatory Resistance (IMR) and/or acetylcholine testing for vasospasms.

[c]Other cardiac diseases reported in a string variable, which included (atypical) angina pectoris ($N = 10$), arrhythmias ($N = 7$), pericarditis ($N = 2$), Takotsubo ($N = 1$), leaking heart valve ($N = 1$).

3.2 | Healthcare experiences and needs

First, the process map and secondly the analysed themes classified within the patient journey will be described.

3.2.1 | Process map

After a thematic analysis, a process map was created based on all 36 individual stories. It visualises (Figure 1) all mentioned steps and actions (*touchpoints*) during the healthcare journey. The presented touchpoints were not necessarily experienced in the same order or by all respondents. The process map begins at the 'start' point (top left) and arrows indicate the direction of the process. Dashed arrows indicate loops/alternative pathways that were experienced by some but not all patients. A loop or alternative pathway often ends with a connector (grey circle with red number) which leads back to an earlier corresponding touchpoint (indicated with a matching bold red number). This process map ends with 'follow-up' (bottom right). Follow-up encompasses treatments with allied HCP but also lifestyle changes and adjustment to daily living. The process map will be described.

Symptom onset (starting point) was followed by the decision to contact a HCP. In most cases, a general practitioner (GP) was consulted who performed or referred for cardiac testing (e.g., blood pressure, blood tests, electrocardiogram, exercise test) or decided to wait longer and sent the patient home. Sometimes the GP did not expect the symptoms to be cardiac-related and referred the patient to another specialist (e.g., gastroenterologist, pulmonologist, internist). Some patients decided to directly visit the emergency department. HCPs in secondary care often could not justify the symptoms because of lacking knowledge about specific INOCA signs and symptoms. Patients were then sent home or referred back to the GP. Consequently, the majority of participants (84%) experienced several repeated loops of referrals between different HCPs and/or being sent home. Only six patients (16%) had a short trajectory and were early seen by a cardiologist specialised in INOCA.

During the diagnostic phase, a definitive diagnosis is made based on symptoms and/or on coronary function testing. Post-diagnostically, a drug treatment was initiated, and some patients were referred to allied healthcare providers (e.g., psychologists, occupational- and physiotherapists), or to a specialised INOCA nurse practitioner (only available in Radboudumc). The Process map ends with "follow up" including all processes after primary drug prescription (e.g., psychosocial treatment, physiotherapy, disease acceptance processes, adjustment in daily living).

3.2.2 | Patient journey map

Whereas process mapping was used to represent all touchpoints and their sequences (Figure 1), the second step adds a layer of experiences and needs to the patient journey so future design challenges could be provided in a last step. Themes, representing patients' experiences and needs, are described in a patient journey map (Figure 2). For each main phase (columns; symptom onset, pre-diagnostic, diagnostic, post-diagnostic) the *touchpoints*, analysed themes, experiences, Pickers' eight PCC principles, and design challenges are represented in separate rows. In this section the analysed thematic themes will be further described per phase. In the supplementary file (Table S2) additional quotes supporting the findings are given. Analysed themes will be further linked to the PCC principles and design challenges in the discussion. This will give clinical and research implications for future quality improvements and implementation research studies.

Symptom onset phase

Sudden symptoms. First symptoms are often sudden and not directly interpretable. Participants reported loss in condition and energy, notified during sport and/or work activities. The patients' environment noticed the symptoms and often advised to slow down or contact a physician. "*I was quite fanatical with running and such, and at a certain point I could not do that anymore and I really did not understand anything about it*." In some cases, thoracic symptoms continued to exist after percutaneous coronary intervention for obstructive coronaries. Most reported symptoms include chest pain, fatigue, shortness of breath, palpitations, and radiation of pain. Symptoms are experienced during rest or physical activity. In addition, emotional stress provoking the symptoms was frequently reported.

Pre-diagnostic phase

Lack of familiarity/knowledge. More than half of the patients reported a lack of familiarity and knowledge regarding INOCA within HCPs. This was experienced during consultations with GPs, emergency physicians, and/or cardiologists. Consequently, symptoms were not recognised or incorrectly attributed to other conditions (e.g., menopausal, gastrointestinal, psychosocial, thyroid problems). "*I have the impression that nine out of ten healthcare providers, especially GP who are a bit older, really don't know what it's about uh then quickly dismiss it as a woman's thing and especially with women in menopause* [….]."

Repeated hospitalisation, testing, and referrals. Repeated hospitalisation, (non)invasive testing, and referrals between HCPs were reported by 60% of the participants. During repetitive hospital admissions, mostly via the emergency department, routine cardiac testing was performed, but did not explain their symptoms. Because of these repeated healthcare processes and symptoms consistently not being acknowledged, patients felt insecure and frustrated. They felt insecure about whether their symptoms might be just "*in their head*," and about their immediate social environment and HCPs would believe they were feigning their symptoms. One patient reported to feel embarrassed because of calling the emergency department five times. As a result, patient delayed contacting an HCP when symptoms worsen. "*Yes, if you have undergone a catheterization five times you are also a bit fed up. And at some point, you believe nothing will come out anymore and then you won't call the doctor anymore.*" This was not experienced by six patients who were directly seen by a specialised cardiologist.

Standard protocols. According to the participants "*they do not fit in*" the current existing guidelines for cardiac diseases.

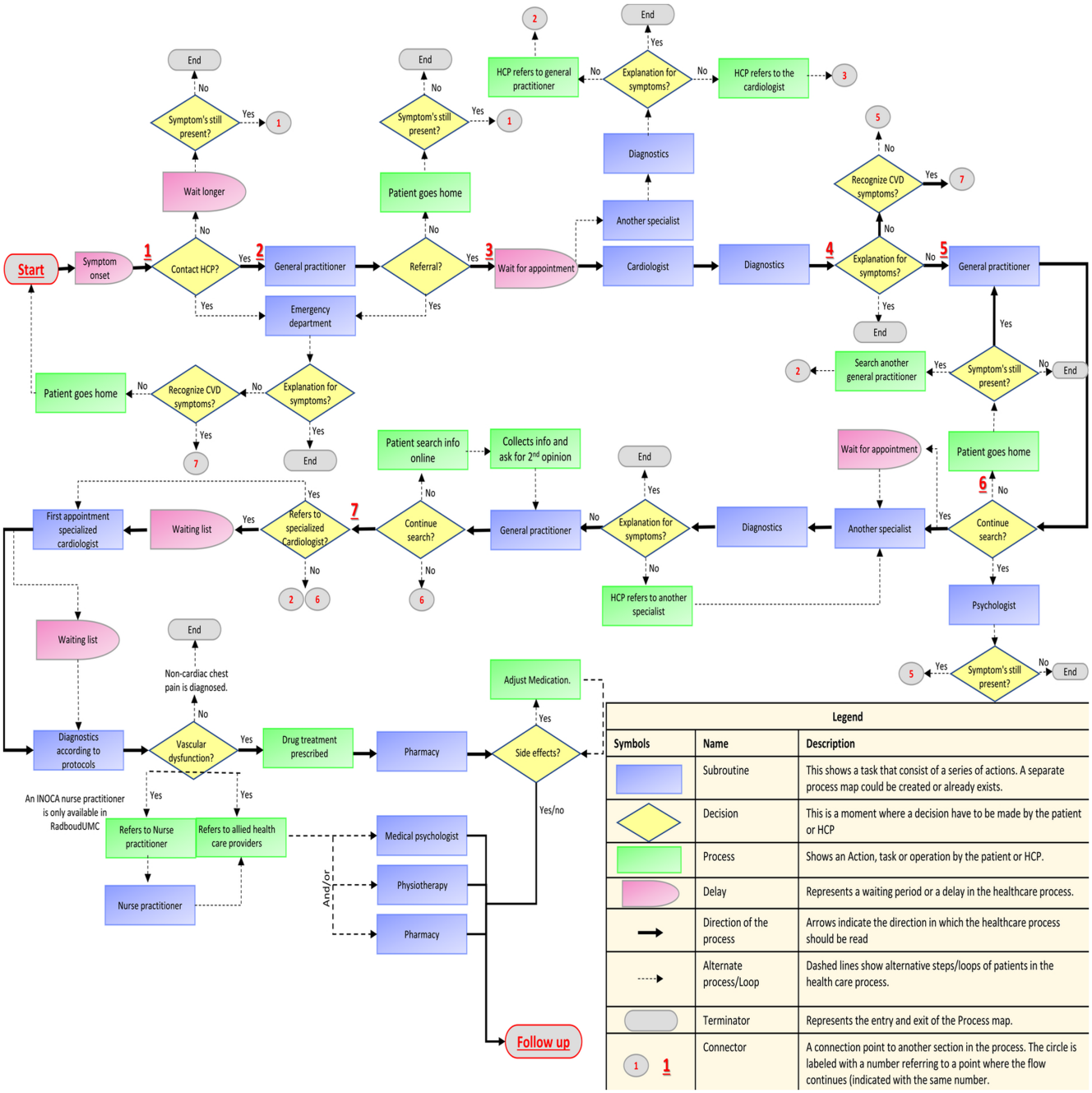

FIGURE 1 Process map of patients with (suspected) INOCA. CVD, Coronary Vascular Dysfunction; HCP, Healthcare Provider

Consequently, their symptoms are not properly addressed. As an example, routine cardiac testing was mentioned not being sensitive for detecting vascular dysfunction. As one patient puts it: "*these tests are aimed at detecting cardiac diseases that are mainly seen in men.*" Another frequently reported example was the standard prescribed "*medication cocktail*". Another patient mentioned: "*yes my husband went home with the same bag of medication as me [...] the dose might be slightly higher or lower [...]. Everyone I know with heart problems went home with the same bag that I started with [...] that is not right.*"

Assertiveness. During the healthcare journey assertiveness was often mentioned in the context of suggesting (new) referrals and/or a second opinion with a specialised cardiologist. If suggested, some experienced resistance by their GP.

"[...] *I wanted to go to a cardiologist specialised in women heart. The GP said: 'why would you want that, what does it matter?' I found his reaction bothersome, but that is what I wanted and searched online and ended up at a specialised cardiologist.*" However, others did have more positive experiences and mentioned direct taken actions and involvement of their GP.

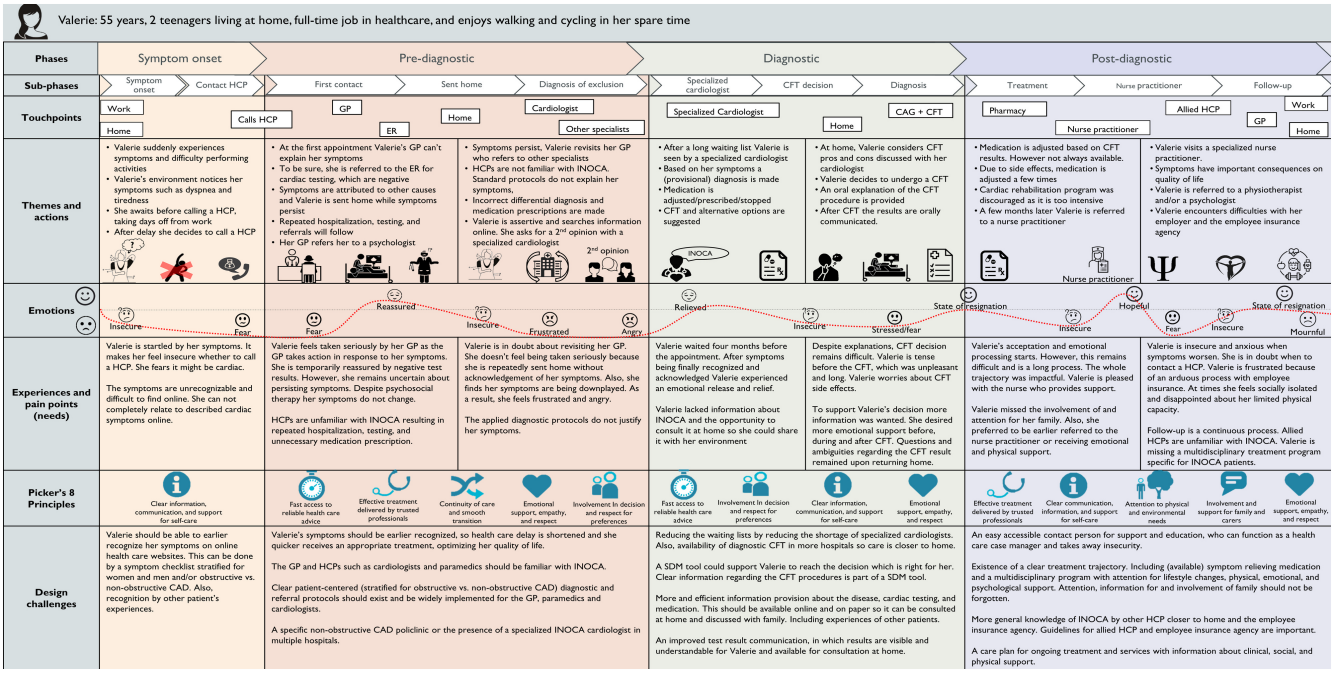

FIGURE 2 Patient journey map: Experiences and needs of patients with (suspected) INOCA. CAD, coronary artery disease; CFT, Coronary function testing; CVD, Coronary Vascular dysfunction; GP, general practitioner; HCP, Healthcare Provider; SDM, shared decision making

Not being taken seriously. During the pre-diagnostic phase, 70% expressed the feeling of not being taken seriously. According to the patients, three factors accounted for these feelings. First, being (repeatedly) sent home after negative diagnostic tests (e.g., cardiac enzymes, electrocardiogram, exercise test and/or coronary angiogram) and no symptom justification. "*Yeah, uh…, the cardiologists in uh at the local hospital who uh only just checked uh if everything is technically okay. The blood is good, and electrocardiogram is correct. Then they do not have to do anything else, they send you home again. Then you don't feel taken seriously.*" Second, not recognising, acknowledging, or sometimes "*downplaying*" the symptoms by healthcare providers. "*Yes, look, at the moment that they [referring to cardiologists] were so derogatory about it, then I didn't feel taken seriously.*" Third, participants indirectly implicated prejudgments HCPs might have about "*this kind of women*" and about their symptoms being "*nothing.*" "*oooh there's that woman again" [quoting a cardiologist]. I thought, well what is this. They look at you in a certain way.*"

Diagnostic phase

Shortage of specialised cardiologists. Linked to the 'lack of familiarity/knowledge' theme participants agreed that there are too few cardiologists familiar with INOCA and that knowledge regarding cardiac sex and gender differences is insufficiently implemented. Consequently, patients experienced waiting list up to 12 months and expressed an important need of specialised care closer to home. "*You experienced a really long waiting time, I have had that too […] There should just be cardiologists and GPs in Breda, Venlo, everywhere, who know about this, who takes this seriously, and know what to do with it. What the treatment should be.*"

Shared decision making; coronary function test (CFT). Crucial decision moments were discussed in the context of shared decision-making. The decision whether to undergo an invasive CFT was frequently mentioned. Patients often felt involved in the decision wherein the cardiologist offered different options (e.g., watchful waiting, medical therapy, or a CFT). Importantly, risks and benefits were discussed upon which patient could decide. However, the possibility of rereading and discussing this information at home prior to making a decision was suggested. Additionally, more information about the procedure and consequences is desired, but the degree to which differed per person.

Treatment and follow-up phase

Multi- and/or interdisciplinary treatment. "*What I also find very unfortunate is that uh for INOCA and for the heart cramps there is no appropriate rehabilitation […] yes like a treatment trajectory, I don't think this exists. It would be nice if there was one.*"

The majority agreed that current cardiac rehabilitation programs do not fully meet the needs of INOCA patients. A mismatch was mainly experienced for physiotherapy. As for other HCPs, physiotherapists lacked knowledge about INOCA diseases healthcare. Consequently, participants were treated similarly as patients with obstructive coronary artery disease. This was experienced as too intensive because it predominantly focusses on rebuilding stamina, exercise capacity, and pushing physical limits. As one patient puts it "*this is just counterproductive for us you know.*" Instead, physiotherapy should according to the partcicipants focus on setting and learning personal and

physical boundaries. Because of the intensity some patients did not complete the rehabilitation, two patients have suffered from burnout complaints, and others were advised not to participate by their cardiologist. Additionally, patients felt they could not identify with the other fellow patients because they were older, mostly men, and suffered from other cardiac diseases.

Beside physical therapy, patients also addressed needs and experiences related to psychosocial well-being. Overall, 17 patients consulted a psychologist. Reflecting on the post diagnostic phase, participants would have preferred to receive information about the possibility of visiting a psychologist in an earlier stage. Also, it was difficult to find a psychologist closer to home who knew about INOCA and its psychological influence and consequences. Support is needed for distress (e.g., anxiety, depression), acceptation, emotional processing, and relaxation.

Positive aspects of cardiac rehabilitation were the assembly of different HCP in one place (multidisciplinary approach), regaining trust in their own body functioning, and lastly learning about new personal boundaries.

Contact person/nurse practitioner. Most of the participants agreed on the need for a contact person other than their cardiologist or paramedic HCP. Post-diagnostically, patients were uncertain about their symptoms, medication, and physical functioning. During these uncertain moments, the possibility to contact an easily accessible HCP (e.g., a nurse practitioner) was wanted. One patient compared it to a nurse specialised in breast cancer (mamma care nurse) who provides support, education, and information and functions as a case manager throughout the course of the healthcare trajectory (e.g., for referrals to allied HCPs). In addition, a nurse practitioner could be helpful to inform allied HCPs who are not familiar with INOCA.

Influence on daily functioning. Patients reported problems in mental, physical, and social functioning. The extent to which symptoms affected daily functioning was person dependent. While some patients made mild changes, others made difficult compromises between their symptoms and desired level of functioning. Impaired physical functioning and fatigue led to restrictions in, for example, sportive, working, recreational, and household activities. Consequently, one participant mentioned being more socially isolated, which was affirmed by another participant. Regarding psychological consequences patients reported anxious and depressive symptoms (e.g., irritability, sleep disturbances, lower self-esteem, impaired cognitive functions, and tearfulness). Many participants used the terms 'acceptation,' 'emotional processing,' and 'grief processing' to describe ways to cope with their chronic condition and its limitations. One patient described it as follows: "*you have to distance yourself from so many things, […] Your entire world is just turned upside down*." Others said: "*I could not accept that I could not work anymore, not being a mother to my children […] and not being able to go for a run*." "*At once confronted with the fact that life is no longer the way it used to be. That you can no longer do what you could and that you must accept that and that is terribly difficult. […]*."

4 | DISCUSSION

In this focus group study, experiences and needs of patients with INOCA were investigated. Identified themes were further classified in a patient journey map. Overall, for most INOCA patients, the process and patient journey map show a complex and long journey with multiple healthcare system contact moments possibly leading to unnecessary high healthcare cost. In addition, we discovered important themes across the healthcare pathway which have policy and design implications. The findings contribute to further optimization of the healthcare pathway towards a more patient-centered care system which is currently lacking. The results will be further discussed in relation to Pickers' eight principles of PCC (Figure S1) and previous research. Furthermore, design challenges will be provided.

Clear information provision and education was a returning need throughout the journey. For example, understandable information about the disease, diagnostic tests, medical results, and treatment options. In addition, more and earlier information regarding alternative resources to help managing their condition and support for self-care were mentioned (e.g., nutrition, physical and mental advises). Better information provision and patient education was also expressed in a report by the coalition of Women Heart (2021). Based on a convening with diverse HCP and patients, the need of better information provision about risks, symptoms, testing, referrals, and disease management were also reported. Lastly, according to participants in the current study, it is important that information is supported by visual context and includes experiences of fellow patients.

Another need was the *continuity and smooth transition* during the healthcare journey. The unfamiliarity of HCPs with INOCA was a major problem due to late recognition of symptoms and delayed referrals. Therefore, patient-centered (stratified for obstructive vs. non-obstructive coronary artery disease), diagnostic, and referral protocols should be implemented for GP, paramedic HCPs within emergency departments, and cardiologists. The unfamiliarity with INOCA by HCP was also reported by Johnson et al. (2021). For example, limited knowledge and insufficient training regarding physical examination and differences between men and women were stated. Moreover, a single point of contact is highly needed and can be completed by a nurse practitioner. Patients who were supported by a specialised nurse practitioner endorsed the support, coordination, and education in their treatment. Lastly, confusion exist about when and who to contact after diagnosis and primary treatment. A clear plan for ongoing treatment and services should be made consisting of information about access to clinical, social, and physical support.

Emotional support, empathy, and respect reoccurred in the entire journey. Pre-diagnostically participants wanted their symptoms to be taken seriously and respected. Emotional support and empathy also played a role before, during, and after the coronary function test. Participants expressed the need to be supported in the acceptance and coping process, which can be executed by a psychologist. However, future research could focus on which psychosocial intervention are most effective. Likewise, *support in physical and exercise*

activities was reported including pain management and help with performing physical activities.

Emotional and physical support should, according to the patients, be integrated into an *effective (adjusted) multidisciplinary treatment* program. Participants agreed that current cardiac rehabilitation programs do not fit INOCA-related symptoms (higher prevalent in women). This might be explained by the finding that women remain underrepresented in cardiovascular trials (Legato et al., 2016). Consequently, physical goals in guidelines for cardiac rehabilitation are mainly based on male standards and may not suit female cardiac patients. Multiple studies have shown higher drop-out rates and non-participation for women in cardiac rehabilitation programs(Resurrección et al., 2017; Supervía et al., 2017). However, the experienced misfit is contradictory to the repeated found benefits of cardiac rehabilitation programs within INOCA-patients (Beltrame et al., 2021). Therefore, future research could focus on explanations for the misfit and will have to show whether sex and gender differences may play a role. Lastly, earlier observed barriers for participation in a cardiac rehabilitation program, such as older age- and male-dominated participation, distance to the program, and physically too heavy exercises, are in accordance to our findings (Resurrección et al., 2017).

Besides a multidisciplinary program, *effective treatment delivery* should also focus on drug prescription and reported side effects. Pre-diagnostically, participants reported identical drug prescription compared to men. However, compelling evidence show that women respond differently to cardiovascular drugs because of sex differences in pharmacokinetics (drug uptake) and pharmacodynamics (drug effect and action)(Tamargo et al., 2017). We therefore stress the importance for better implementation of personalised drug prescription to optimise patient experiences and QoL. Furthermore, current guidelines still do not address INOCA-related diseases and important treatment trials are lacking (Bairey Merz et al., 2020). Existing stratified therapy may be symptom relieving and improve QoL. An effective multidisciplinary and medical treatment ask for better coordination and integration of different care disciplines considering a holistic view in the treatment and patients experiences.

Another important principle for PCC is *Access to care* which depends on; availability, accessibility, affordability, and acceptability (Gulliford et al., 2002). Regarding service availability, waiting lists due to a shortage of specialised cardiologist, and lacking knowledge and unfamiliarity within HCP were reported. Consequently, needed care is not always close to home and difficult to access. Additionally, variations in referral practices from primary to secondary care might also be a barrier to accessibility of care. This is in line with findings of the aforementioned report by Women Heart (2021), where limited access to care was explained by insufficient facilities and providers in local area. In addition, the report states that financial resources also played a role. However, this was not found in the current study. The distinct findings might be explained by important differences in healthcare insurance policies between the two different countries.

Patients wanted to be *involved in decision making* when not in an acute situation. The decision whether to undergo specific coronary function testing together with referral and treatment options (medication and allied care) were mentioned. This study and its results will be used in the development of a shared decision-making tool for coronary function testing.

4.1 | Limitations

No men were included in the study. Even though more than two third of the INOCA patients are women, this might potentially have influenced the results. In addition, included participants were overall higher educated and white assertive women. Consequently, this might limit the generalizability of the results since women from lower socioeconomic status, other ethnicities, and people with limited ability to access the healthcare system were not included. Because we used a qualitative design, conclusions about the perceptions are not representative for all INOCA-patients. In future studies methodological triangulation with structured questionnaires (e.g., Patient Reported Outcome and Experience measures) should be used to ensure better validity. Nevertheless, other techniques to enhance trustworthiness such as member- and peer checking, maintaining a research diary wherein important decisions are documented, and analysis by different individuals were performed (Howitt, 2016).

5 | CONCLUSION

Various experiences and needs were identified within INOCA-patients and are represented in a patient journey map. Overall, the results show a complex and long healthcare journey with multiple implications for quality improvements. More familiarity and knowledge regarding INOCA as well as better information provision is needed. In addition, an adequate referral system in both early and later stages of the pathway seem to be important for earlier recognition. Two other major findings were the need of an easily accessible contact person and a multidisciplinary treatment program adjusted to the needs of INOCA-patients. The resulting visual tool can help healthcare professionals and researchers improve healthcare provision which is patient-centered and tailored to the preferences of INOCA-patients.

6 | RELEVANCE TO CLINICAL PRACTICE

Based on the healthcare experiences and needs of INOCA-patients different design challenges were suggested. This includes earlier recognition, improved information provision, clear referral and diagnostic protocols, and better follow-up care. Implementing these design challenges in healthcare and hospital policy may contribute to better patient experiences. This has several practical implications. On a patient and treatment level, it may contribute to better quality of life, outcomes, and adherence to medication and suggested lifestyle changes. On an organisational level, it may lead to fewer readmissions and diagnostic testing, better

experiences within healthcare providers, and more cost-effective care. It should be kept in mind that this study was conducted in the Netherlands and that implications to other countries and continents may be different. It can be hypothesized that the health care needs and experiences will be similar for other countries. However, due to differences in healthcare systems, organisations, access to care, and healthcare costs other experiences and needs may be more important.

AUTHOR CONTRIBUTIONS

The authors confirm contribution to the paper as follows: Conception and design of the study: D. L. van Schalkwijk, P. M. C. Mommersteeg, B. L. den Oudsten; J. Slatman, J. W. M. G. Widdershoven; Data collection: D. L. van Schalkwijk, P. M. C. Mommersteeg, W. M. G. Widdershoven, M. Hartzema-Meijer, S. Elias-Smale; Analysis and interpretation of results: D. L. van Schalkwijk, P. M. C. Mommersteeg, B. L. den Oudsten, J. Slatman; Draft manuscript preparation: D. L. van Schalkwijk, P. M. C. Mommersteeg, J. W. M. G. Widdershoven; Critical revision of the article: D. L. van Schalkwijk, J. W. M. G. Widdershoven, S. Elias-Smale, M. Hartzema-Meijer, B. L. den Oudsten, J. Slatman, P. M. C. Mommersteeg; Final approval of the version to be published: D. L. van Schalkwijk, W. M. G. Widdershoven, S. Elias-Smale, M. Hartzema-Meijer, B. L. den Oudsten, J. Slatman, P. M. C. Mommersteeg.

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CONFLICT OF INTEREST

None declared.

DATA AVAILABILITY STATEMENT

Raw data (audio recordings and transcripts) cannot be shard publicly due to the privacy of individuals that participated in the study. Data such as the used codes (in Dutch) will be shared on reasonable request to the corresponding author.

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