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Designing remote patient and family centred interventions: an exploratory approach

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Abstract

This research explores the dynamic nature of family involvement in remote patient management for cardiovascular disease and its impact on lifestyle behaviour changes. Through an interview study with patients and family members, we categorise family involvement into three types: Inform, Integrate, and Influence, highlighting the dynamic and heterogeneous nature of family involvement across different phases and activities. Overall, we emphasise the need for personalised and adaptable interventions to cater to the diversity of families and propose a modular approach to remote monitoring design.

Keywords: family involvement, remote patient management, cardiovascular disease, human-centred design, health services

1. Introduction

Limited adherence to the cardiovascular disease (CVD) health management process is a major challenge worldwide (Kotseva et al., 2019). Despite significant efforts within the current healthcare system to encourage positive lifestyle changes, many patients struggle to embed these changes into their daily routines (Rippe, 2019). In tackling the problem of adherence, existing interventions and services overlook the potential benefits of explicitly incorporating family members into the care team (Deek et al., 2016). This could result in missed opportunities for improved health management and, thereby, better health outcomes for the patient and possibly also for the family (Kokorelias et al., 2019).

Studies show that the involvement of the family could enable long-term adherence to health-related behaviours (Middleton et al., 2013). Besides, the emergence of technological innovations is driving significant transformation in the healthcare sector, including the development and adoption of Remote Patient Management (RPM) services for care at home (Vegesna et al., 2017). In the context of CVD, RPM services have the potential to change the way patients and their families collectively manage necessary lifestyle adjustments following a cardiac event (Akinosun et al., 2021; Sin et al., 2018).

Research endeavours focusing on integrating family members into patient care trajectories have predominantly assessed their needs as “caregivers” and the burden they bear (Kokorelias et al., 2019). Although pivotal, studies often overlook the broader influence of family involvement in the patient's daily lifestyle activities at home, especially when viewed through the lens of behaviour change.

To truly understand family involvement, we must understand the complex familial CVD trajectory. This trajectory consists of changing circumstances and requirements, such as the illness stages and associated coping, that patients and their families face while managing the disease (Birtwistle et al., 2021; Fleury

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and Moore, 1999). It encompasses their evolving needs, preferences, and challenges encountered at different stages of the CVD journey. This dynamic nature of the health trajectory necessitates a comprehensive understanding of the preferences for family involvement in facilitating behaviour change, especially for sustained adoption and use of services and interventions (Lee and Lee, 2020; Lee, 2019; Van Gemert-Pijnen et al., 2011). Recognising the importance of family involvement in health management, especially in the home context, this article explores the following research question: *How can long-term adherence to lifestyle behaviour change be realised by involving families in CVD health management through an RPM intervention?*

To understand these challenges and contribute to the field, this research has as its primary objective to investigate the various facets of family involvement in chronic health management, including their needs and preferences for lifestyle behaviour changes throughout the CVD trajectory. The study seeks to provide valuable insights by exploring the experiences and interactions of patients and family members across the cardiac health trajectory.

This paper is structured as follows: first, we describe the research design consisting of the theoretical framework and the generative interview study method. Then we present the research findings, and finally, we discuss the study results, which lead to actionable design guidelines.

2. Research design

2.1. Theoretical framework

To explore how family members influence each other's health behaviours, we build upon the theory provided by the Dyadic Illness Theory (Lyons and Lee, 2018) and the Heart Failure (HF) Care Dyadic typology (Buck et al., 2019). This theory views illness management as a dyadic phenomenon between patient and partner; it considers health to be influenced by their collective behaviour as an interdependent dyad. This understanding is articulated by the HF Care Dyadic typology by classifying patient-partner interactions in four ways based on their individual and relational orientation regarding self-care (Buck et al., 2019).

To examine family dynamics through an influence perspective and shape the classification of the family contexts, we built on the underlying theory of these classifications. We followed a constructivist designerly approach (Jung et al., 2022) to employ two axes for analysing family units: the X-axis (Alignment) at an individual level and the Y-axis (Involvement) on a relational level. By Alignment, we refer to the extent to which family members exhibit positive health behaviours themselves, relative to each other. This dimension recognises the significance of a cohesive family environment that facilitates and supports behavioural changes. By Involvement, we refer to the level of collaboration the patient receives from the family member, determining the extent to which a family member is involved with the patient's health-oriented lifestyle. The axis acknowledges that the active support and engagement of family members can impact the patient's health. The resulting classification is presented in Figure 1.

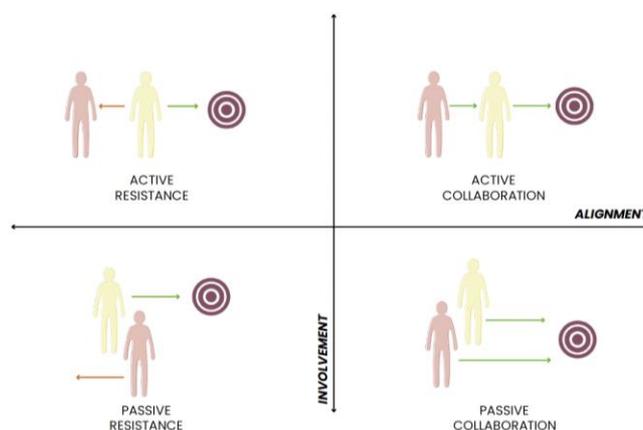


Figure 1. Classification of types of family influences on behaviour change

The classification led to four possible types of family influence encompassing the possible social qualities of a patient-family member relationship from the perspective of their influence on health behaviour. These are explained in Table 1.

Table 1. Four types of family influence

Axis	Quadrant	Description	Illustrative Examples
X-Axis Alignment	1. Active Collaboration	This type of influence would mean that the family member(s)' lifestyle is closely connected with the patient's lifestyle, and they collectively engage in positive health behaviours.	The patient expresses interest in cycling as a form of regular exercise. The patient and partner research cycling routes together and schedule cycling together to motivate each other.
	2. Passive Collaboration	This type of influence would mean that the family member(s)' lifestyle is not inter-linked with the patient's lifestyle, and they independently engage in positive health behaviours.	The patient expresses interest in cycling as a form of regular exercise. The patient cycles during the time that partner attends yoga class.
Y-Axis Involvement	3. Active Resistance	This type of influence would mean that the family member(s)' lifestyle is intricately connected with the patient's lifestyle, but the family members do not engage in positive health behaviours.	The patient expresses interest in cycling as a form of regular exercise. However, the partner repeatedly expresses safety concerns, which becomes a barrier to the patient's physical activity goals.
	4. Passive Resistance	This type of influence would mean that the family member(s)' lifestyle is not linked with the patient's lifestyle and the family members do not engage in positive health behaviours.	The patient expresses interest in cycling as a form of regular exercise. However, the spouse neither encourages the patient nor engages in any physical activities themselves.

2.2. Interview study

To empirically test this classification and address the research question, this study consists of 8 semi-structured generative interviews allowing participants to reflect deeply on their family involvement in health-related activities and how this evolved throughout their health trajectory. The research was conducted in accordance with and with approval of the ethical guidelines set by the Human Research Ethical Committee (HREC) at TU Delft.

2.2.1. Participant sampling

Participants for this research were selected using a key informant strategy, following [Patton's \(2015\)](#) definition of individuals possessing substantial knowledge or influence relevant to the research topic. Patients and their family members were recruited through the support of the Product Evaluation Lab at the Delft University of Technology. Key informants were considered eligible for the study if they met two criteria: (1) they had experience with CVDs either personally or within their home context, and (2) they had at least one family member cohabiting in their home environment or cohabiting in multiple households. A final sample of 8 participants (6 patients and 2 partners) was selected for the interview process, with 2 of these patients being accompanied by their partners during the interviews.

2.2.2. Data collection

Data collection involved semi-structured interviews, each lasting 60-90 minutes. These interviews were designed to maintain consistency and rigour by following a predefined set of open-ended questions and prompts, ensuring that relevant topics were covered with each participant. Data collection included a generative activity using matrices, inspired by the previously presented theoretical classification. Each matrix was designed to unveil the social influence context of each participant concerning family involvement per risk-moderating lifestyle activity. Following the path of expression as proposed by [Sanders and Stappers \(2012\)](#), the initial part of each interview investigates the participants' existing habits and lifestyles. Subsequent segments, guided by reflective questioning, encouraged participants to position themselves on the matrix. This positioning aimed to assess their personal and relational circumstances across five risk-moderating lifestyle activities, identified from a cardiovascular perspective – (1) Diet, (2) Physical Activity, (3) Health Monitoring, (4) Medication and (5) Smoking. Participants were then asked to evaluate their past experiences with their current status. and articulate their preferences concerning changes in family involvement to achieve health goals. This activity was replicated for each of the five lifestyle activities.

2.2.3. Data extraction and analysis

The data extraction process encompasses two components. Firstly, it involves the examination of the generative content generated during the interviews. Secondly, it entails the analysis of the audio recordings of the interviews. The audio-recorded interviews were subjected to a systematic process following the grounded theory methodology outlined by Birks and Mills (2015). This included extracting noteworthy quotes that reflected preferences and experiences of family involvement, for example; “we (wife) will often talk about you know how we're nowhere near our step goal and therefore it will decide on who goes and takes the dogs after dinner for a walk to kind of get some more steps in”. Here the participant emphasises their shared commitment to stay active, thus capturing real-life scenarios to enrich the insights regarding family involvement. Similarly selected quotes were associated with corresponding words or short phrases, referred to as “codes”. Subsequently, these initial codes were categorised into intermediate clusters based on their collective ability to define a concept and uncover meaningful insights within the data set. Once the clusters are established, an overarching title is added to elaborate on the coding content of that category. The final step is constructing a theory based on the links between the different categories. While following this step, an alternative approach to linking categories was employed, as is customary in Grounded Theory Methodology. In this research, the categories were thematically compared to the phases of the patient's illness trajectory to capture the relational nature of these preferences over time.

3. Results

3.1. Matrix outcomes

Figure 2 below combines the results of the generative matrix activity to illustrate the participants' self-assessed positions within the matrices.

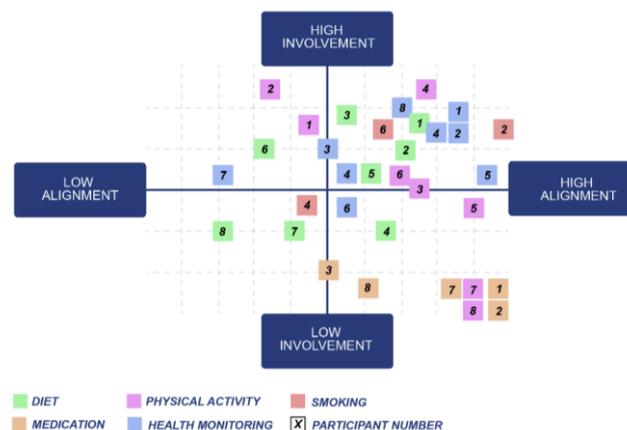


Figure 2. Results matrix activity involvement

All 8 participants positioned their involvement in the five lifestyle activities on the axes¹. Wide differences in involvement were observed across different risk-moderating lifestyle activities, both within and across family contexts. These results show heterogeneity in families' preferences regarding involvement levels across specific lifestyle activities.

3.2. Interview outcomes

The primary coding of the interview transcripts yielded 40 primary codes, which were subsequently clustered and labelled into 11 overarching categories, representing distinct examples of family involvement in a patient's health journey. These categories could be further represented by 3 overarching themes of Family Involvement: (1) Types, (2) Phases and (3) Moderators. The overview of the results is presented in Table 2 below.

¹ Not all participants were dealing with smoking and medication, hence the absence of data points.

Table 2. Interview outcomes

Theme	Category	Description	Illustrative Quote
Types	Inform	Involvement focused on communication and information sharing.	<i>"for instance, I went to see the doctor yesterday about some about some things, and uh, I just send immediately when I get back, I send a message to the wife.... 'That's what's happening next' ... 'This is what the doctor thinks'"</i> (Patient 3)
	Integrate	Collaborative involvement is characterised by shared decisions and goals.	<i>"I think we're both aligned on that. We try to eat vegetables every day, we eat less meat than we used to, and that's substituted by fish or chicken or even vegetarian, although we're not vegetarians"</i> (Patient 4)
	Influence	Situations where family members' actions directly shape the choices made by the patient.	<i>"if we are walking together then I can say.. Hey, if we do a bit more steps then we are above the 10,000, at least for me.. so we think okay! so it's taken into our actions but he doesn't want to monitor it himself."</i> (Partner 1)
Phases	Pre-Diagnosis	Period before a specific health condition is formally diagnosed	<i>"I think knowing that (family cardiac health history) for the whole of my life, I've always tried to keep myself relatively fit from a cardiovascular perspective... I knew it was something which is potentially hereditary"</i> (Patient 3)
	Hospitalization and Clinical Interactions	Moments or periods when the patient receives medical attention from a healthcare professional in a clinical setting.	<i>"Yeah, that's one of the first things we do if he is with the cardio doctor or if there's a control for the ICD and everything is OK, then there always is a WhatsApp to the whole family. So they are very much involved and want to be updated"</i> (Partner 1)
	Chronic Health Management	Long-term health management including lifestyle practices in the home context.	<i>"So the days in which you don't have a lot of discipline yourself, it's very helpful when there's somebody in your surroundings that says, well, come on.."</i> (Patient 6)
Moderators	Patient Perception	The extent to which a patient is knowledgeable and conscious of their health condition and treatment options.	<i>"he was really concerned and I couldn't tell him anything either. Once I came back, I said, I don't know, they had a discussion. And I, you know, have to stay night over and then I'll be home if everything goes fine tonight"</i> (Patient 4)
	Patient Coping	The patients emotional and behavioral reaction to their health condition, treatment plans.	<i>"she's in the medical industry a little bit herself. So she understood what was going on, and she understood the risks for me at the time"</i> (Patient 3)
	Patient's self-efficacy	The patient's belief in their own ability to perform tasks in managing their health.	<i>" if I look like I'm sick or I start staggering around. I'd want them to be aware and conscious and do something, you know? But then I'm not expecting them to kind of sit me down and put my blood pressure cuff on and take my blood pressure or do my blood sugars.."</i> (Patient 3)
	Family Coping	Family members' reactions and attitudes of family members toward the patient's health condition.	<i>"I don't tell my mother if I have something because she starts crying and gets emotional, like also overly concerned. And my son, who's abroad? I don't inform because I don't want him to worry"</i> (Patient 3)
	Family Capability	Family members' abilities such as knowledge, resources or willingness required in supporting the patient.	<i>"my wife, she is a nurse. So sometimes I ask her for advice. And my oldest daughter, she's also a nurse so she also knows a lot. So sometimes when I've got questions, I ask them when there's something."</i> (Patient 5)

Table 2 shows that three categories emerged from the interviews, pointing at different ways in which family members are involved in the health of the patient. These were differentiated as (1) Inform, (2) Integrate (3) Influence. Multiple participants described instances of informative involvement, characterised by communication-centric interactions between family members and patients. In these scenarios, patients actively shared health updates, decisions, or changes with their family members. Integrative involvement, on the other hand, represented a more collaborative approach to health management within families. Participants highlighted joint efforts in decision-making processes, such as setting health goals, planning physical activities, and adopting healthier lifestyle habits. This collaborative engagement was also exemplified by participants using instances of dietary modifications and physical activity. The last type of involvement emerged as a consequence of the actions of a family member, which would impact the patient's decision or activity. While all participants shared instances of positive influence on activities such as physical activity, two patients also recalled examples of what they recognised as avoidable influences, such as diet and smoking.

Table 2 also shows three phases, highlighting the phase-dependency of family involvement. Participants shared instances that could be characterised based on the period in time in which the involvement occurred, thus emphasising the dynamic nature of family involvement. Patients' perspective on family involvement during clinical interactions was also varied. Some patients, like Patient 3, indicated that having a family member, particularly someone with medical knowledge, can provide emotional support and help in understanding the situation better. Conversely, the study also identified patients who expressed reservations about excessive family participation during clinical interactions. Notably, the same patient recognised the essential role of family involvement in home-based health management, particularly in emergencies.

Finally, Table 2 shows five categories of involvement moderators. The examples of family involvement were often accompanied by anecdotes representing the patient's reasons or hesitations to involve a family member in their health. These moderators of involvement were attributes of patients or family members that played a role in determining types of family involvement. The categories of moderators are collectively indicative of the motivations and deterrents behind family involvement in health-related activities and suggest that underlying personal factors can shape these interactions.

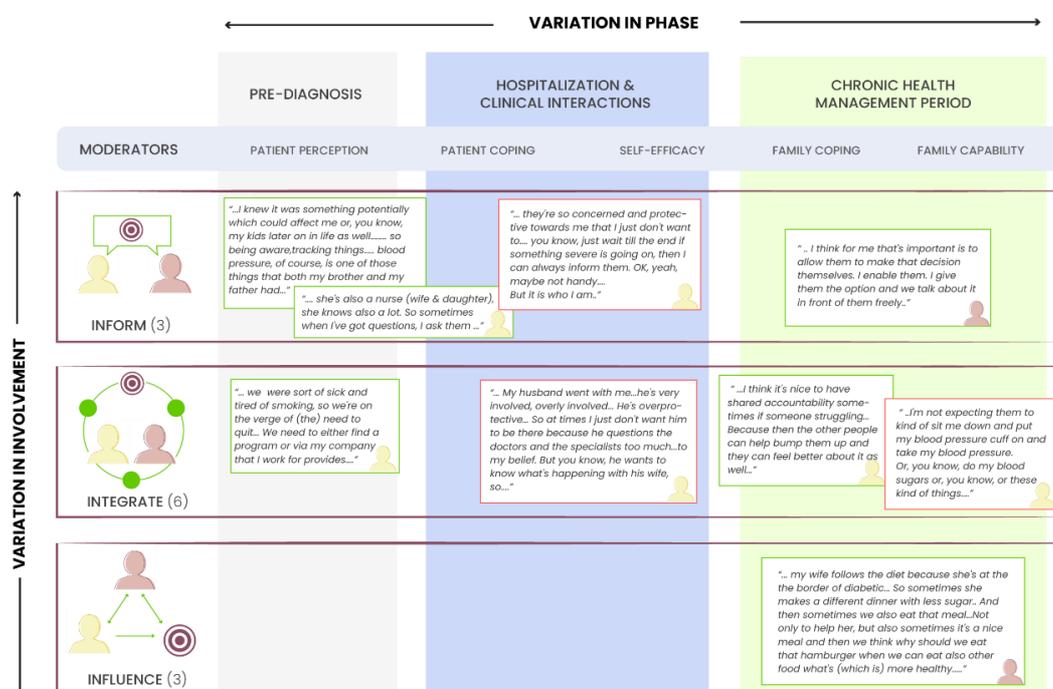


Figure 3. Types of family involvement over the CVD trajectory

4. Discussion and conclusion

The findings of this qualitative study show that focusing on family influence on daily lifestyle activities, rather than solely seeing family members in their caregiver role, could lead to a more nuanced understanding of contextual distinctions especially relevant for behaviour change initiatives. By investigating the consistency or its lack thereof in family involvement across various lifestyle behaviours throughout the CVD trajectory, we sought to shed light on the dynamic nature of family engagement in long-term health management.

As such, the results of the generative interview studies revealed heterogeneity in the types of family involvement in CVD patients' health journeys. Specifically, the three identified types of involvement; Inform, Integrate and Influence, provide insights into different kinds of family engagement. The variation in the types of involvement, indicated by participants across different lifestyle activities, could also be influenced by the moderating effect of inter-personal factors such as patient perception, patient coping, patient self-efficacy, family coping, and family capability. Furthermore, the relevance of the phases of the health journey highlights the evolving needs of diverse family contexts.

The emergent variation in family contexts, across time and lifestyle activities demonstrated in this study aligns with the dynamic nature of the CVD trajectory; both patients and families go through their own and shared journeys. To leverage family engagement for behavioural change, RPM services must truly address the dynamic and heterogeneous needs related to engagement, thereby necessitating personalised and customisable interventions that meet the specific needs and preferences of both patients and their families over time. Therefore, for long-term adherence to lifestyle behaviour change, the nuanced understanding of family contexts based on involvement styles and behaviour influence presents an opportunity for the design of personalised RPM interventions.

To operationalise the findings from the study, we further iterated on our theoretical framework to suggest a classification of family contexts based on involvement preferences and behaviour influences. Figure 4 depicts the three types of involvement when combined with the positive (collaboration) and negative (resistance) alignment in self-care. This resulted in six possible family contexts, representing the relevant needs to be fulfilled to be supported in the process of behaviour change. This systematic classification system is the first step in characterising family contexts based on involvement preference and behaviour influence, thereby outlining corresponding needs. The importance of understanding these familial needs for developing fitting interventions has been identified in previous research by [Versteegden et al. \(2022\)](#). They emphasise the necessity for a strong understanding of the personal needs and nature of relationships before designing interventions for family support.

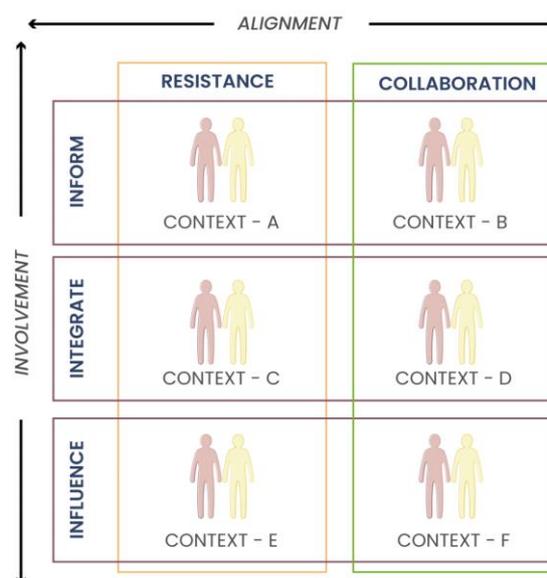


Figure 4. Classification of types of family involvement in health behaviour change

The proposed classification, framing the types of family involvement can be used in the iterative user-centred design process of behaviour change interventions. Using guiding frameworks can support designers with analysing and understanding the problem, and with formulating contextual design requirements for creating meaningful solutions (Haase and Laursen, 2019). Moreover, the framework can be applied as a guide to inform persuasive design choices and tailor interventions for targeted behaviour change (Asbjornsen et al., 2020). For instance, within Context A, where a partner could resist positive behaviour by misinforming the patient about the risks associated with physical activity, an educational intervention tailored to the individual could prove beneficial. Conversely, in Context E, where the patient is directly influenced by the partner's inactive lifestyle, implementing nudges encouraging the partner's participation could represent a preferable design strategy. In the case of Context D, adopting gamification techniques to enhance shared health goals could offer valuable support for the family's health journey.

For long-term adherence, it is essential that an RPM intervention provides the right service modules at the right time, ensuring relevance by aligning with the user's needs and thereby preventing abandonment (Lee, 2019, Van Gemert-Pijnen et al., 2011). To effectively cater to the changing needs for the different family contexts identified in the framework, designing a continuous modular RPM service delivery approach is a key requirement.

In these terms, we highlight the significance of breaking down service components into distinct modules, allowing for greater flexibility and customisation over time (Fricke and Schulz, 2005). These RPM service modules can encompass components such as dietary recommendations, fitness plans, mental health resources, and social support. To give an example of such a modular RPM intervention; imagine the following situation: family Vermeer, who have difficulties with making dietary changes together, is given advice on how best to do this in their situation. Conversely, they are already doing well with exercising together, so for this activity, more attention is paid to sustaining this behaviour through positive encouragement. A couple of months later, the family Vermeer collaboratively improved their diet, so now the service adapts to focussing on sustaining this positive behaviour as well.

Designers can play an important role in developing and adjusting these modules to meet the specific preferences and requirements of individual families. In itself, the concept of service modularity is not novel in digital health design: examples range from modular web platforms for tailored hypertension management (Siopis et al., 2022), to a modular mHealth app service for breast cancer (Lim et al., 2021), to a modular ICT-based framework for diabetes self-management (Lamprinos et al., 2016). Our proposed approach builds on this existing knowledge by showing how it can be applied in designing family-centred interventions for home-based CVD health management. Additionally, in applying our contextual classification, designers are prompted to identify the necessary data points for recognising contextual needs. This step is crucial for creating a dynamic system capable of harnessing adaptive AI features to maintain responsiveness to the evolving behaviour of users (Grua et al., 2020). Such systems should continuously monitor and analyse user behaviour in real-time, making data-driven adjustments to deliver a personalised experience that aligns with the ever-changing preferences and needs of each family context. The explorative and situated Data-Enabled Design (DED) approach, introduced by Van Kollenburg and Bogers (2019), is ideally suited for gathering data and designing interventions and services within this framework, as it leverages data collected from everyday contexts to inform the design of interventions and services. While DED has been applied to family-wide behavioural change interventions (Jansen et al., 2020; Pannunzio et al., 2020), it has not yet been employed to adapt to different types of family involvement, which we characterise as an opportunity for further research.

The research makes a two-fold theoretical contribution to design research. Firstly, it integrates new insights from behavioural science and disease management into the design process. This integration enriches our understanding of family relationships and well-being management, which is particularly relevant as the field of design pursues to include and impact an increasing number of users and their interactions. Secondly, the research provides guidance on user-centred design specifically in healthcare. For instance, it guides the design for the dynamic user needs, which require modularisation, inherent in healthcare environments over time.

While this research provides valuable insights into the potential of family involvement in CVD management and in the design of RPM interventions, several limitations should be acknowledged. The

sample size of eight participants, although carefully selected, is relatively small and limits the generalisability of our findings to a broader population. In addition, while the qualitative data analysis approach used in this study is appropriate for exploring the depth of family involvement, it is subject to interpretation, and other researchers may interpret the same data differently. Further research with larger, more diverse samples and a more longitudinal design could contribute to a better understanding of types of family involvement within CVD.

In conclusion, our study explored the potential of family involvement in the management of cardiovascular diseases through the application of remote patient management (RPM) interventions. We have identified three primary types of family involvement - Inform, Integrate, and Influence - and proposed a classification of types of family involvement to facilitate the development of dynamic, personalised interventions. We point towards a need for further research, applying the identified types of family involvement in RPM interventions and evaluating their impact on various lifestyle activities. Additionally, we note that the systematic collection of family-generated contextual data using the proposed approach could enhance our understanding of health-relevant family dynamics and the diverse responses to behavioural interventions across multiple lifestyle activities. Embracing the intricacies of family dynamics holds the promise of more effective, personalised, and sustainable management of cardiovascular diseases.

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