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Less Supervising, More Caring: Design Recommendations for Informal Caregivers' Co-Participation in Cardiac Telerehabilitation

IRINA BIANCA ȘERBAN*, Eindhoven University of Technology, Netherlands
LONNEKE FRUYTIER*, Máxima Medical Centre, Netherlands
SARA COLOMBO, Delft University of Technology, Netherlands
DANNY AJP VAN DE SANDE, University Medical Centre Utrecht, Netherlands
HARELD KEMPS, Eindhoven University of Technology, Netherlands and Máxima Medical Centre, Netherlands
STEVEN HOUBEN, Eindhoven University of Technology, Netherlands
AARNOUT BROMBACHER, Eindhoven University of Technology, Netherlands

Informal caregivers' engagement with patient data is becoming increasingly central to CSCW and HCI research on health management. Cardiac telerehabilitation (CTR) technologies generate lifestyle and well-being data that support patients and their families in recovery management, yet informal caregivers' roles in CTR remain underexplored. Recreational athletes in rehabilitation are an especially under-researched group, despite their and their support system's unique needs. Focusing on caregivers of recreational athletes, we conducted interviews with ten participants and used six visual scenarios of a dyadic CTR system to explore their perspectives on data and information co-participation. Caregivers reported that co-participation could strengthen dyadic coping and management but emphasized the need to balance important trade-offs. We provide design recommendations for dyadic CTR systems that balance care needs and preferences, promoting caregiver involvement in a supportive, non-supervisory role. We contribute to CSCW research by proposing a conceptual shift in technology-mediated rehabilitation care: positioning caregiver-inclusive CTR systems as negotiation tools that support boundary work and balance competing care values.

CCS Concepts: • **Human-centered computing** → **Empirical studies in HCI**; *HCI design and evaluation methods.*

Additional Key Words and Phrases: Informal Caregivers, Recreational Athletes, Cardiac Telerehabilitation, Caregiver Involvement, Data Interaction

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*Both authors contributed equally to this research.

Authors' Contact Information: Irina Bianca Șerban, i.b.serban@tue.nl, Eindhoven University of Technology, Eindhoven, Netherlands; Lonneke Fruytier, lonneke.fruytier@mmc.nl, Máxima Medical Centre, Veldhoven, Netherlands; Sara Colombo, Delft University of Technology, Delft, Netherlands; Danny AJP van de Sande, University Medical Centre Utrecht, Utrecht, Netherlands; Hareld Kemps, Eindhoven University of Technology, Eindhoven, Netherlands and Máxima Medical Centre, Veldhoven, Netherlands; Steven Houben, Eindhoven University of Technology, Eindhoven, Netherlands; Aarnout Brombacher, Eindhoven University of Technology, Eindhoven, Netherlands.

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1 Introduction

Cardiac telerehabilitation (CTR) has become an essential means for cardiovascular disease (CVD) patients to access cardiac rehabilitation (CR) remotely, particularly post-COVID-19 [41]. Yet, CR is rarely a solitary journey, as patients often rely on *informal caregivers* – family members or friends – for practical and emotional support crucial to successful rehabilitation [7, 86]. Managing pivotal lifestyle adjustments thus becomes a collective endeavour in which caregivers are active part-takers [17]. Despite growing interest from Computer-Supported Cooperative Work (CSCW) and Human-Computer Interaction (HCI) communities in incorporating caregivers in technology-mediated care (e.g., [10, 55, 76]), they remain largely overlooked in CTR design and development [48]. Understanding how caregivers interact with CTR systems that formalise their role could improve CTR solutions, fostering collaborative home health management and better outcomes for the patient-caregiver dyad [53].

Our focus is on the underexplored context of caregivers supporting recreational athletes with CVD, a subgroup often excluded from C(T)R research that typically centres on sedentary populations needing considerable health behaviour improvements [85, 104, 111]. Already physically active, recreational athletes face unique challenges post-diagnosis [78], such as adapting to exercise restrictions that may cause stress and anxiety as they are limited in the activities they love [45, 114]. They must reconnect with their bodies and adjust life priorities while often feeling a lack of empathy and understanding from their families regarding the physical and emotional challenges of these restrictions [65]. Engaging caregivers in these athletes' rehabilitation journey can foster positive dyadic coping and enable caregivers to support the athlete's physical and emotional adjustment to a new lifestyle. This can help athletes maintain engagement with their preferred sports.

CTR relies heavily on complex patient data to support health management and information exchange [19, 30]. Most digital health research has primarily focused on patient and clinician involvement in these processes [2, 56, 102], overlooking the potential contribution of caregivers. Few examples of *dyadic CTR* technologies enable caregiver *co-participation* [35, 113], which we define as *the caregiver's structured access to patient data and monitoring, informational resources, and clinician communication, specific to the caregiver role.* Yet, a critical gap persists: *user-centred* research exploring caregiver perspectives and the broader implications of their co-participation is rare. A 2020 review shows that no CTR studies have examined real-world implementation, focusing only on *post-development* metrics like acceptance and efficiency [101]. CTR's limited readiness for practical, everyday use partly stems from *neglecting pre-development insights* [85] – especially from caregivers – which are crucial for anticipating how the technology could integrate into the 'real world' and address practical and relational needs in CR. This may be especially important for recreational athletes valuing autonomy in data tracking [105, 114]. As CR reshapes the athlete-technology-family dynamic, understanding caregiver co-participation can guide user-centred CTR design, making it better suited for seamless, real-world application.

We unpack CTR co-participation by examining caregivers' unique perspectives on *the advantages and trade-offs of caregiver data and information co-participation in CTR for recreational athletes.* Through qualitative interviews using visual scenarios of co-participation with 10 caregivers, we offer insights into balancing support with autonomy. Our contributions include:

- An empirical description of caregiver experiences during athlete CR. To our knowledge, such experiences have not been documented in previous literature.
- A nuanced view of caregivers' co-participation in technology-mediated care that extends existing CSCW caregiving models.
- Recommendations for caregiver-inclusive CTR technologies that *balance care values* and *support boundary negotiation* through *adaptive, context-aware design*. We propose conceptual

shifts in CTR design that reconcile caregivers' desire to support without overextending their role.

2 Background and Related Work

2.1 Recreational Athletes and Cardiac (Tele)rehabilitation

2.1.1 Tailoring Cardiac (Tele)Rehabilitation. CR programs are designed to promote physical and psychosocial recovery following a cardiac event, as well as to prevent recurrence through sustainable lifestyle changes [19]. Exercise-based CR is highly recommended for individuals with coronary artery disease (CAD), the most prevalent form of CVD, due to its proven impact on reducing cardiac mortality and rehospitalization rates [4, 108]. CR is goal-oriented, striving to build confidence in physical activity, foster self-management, and support a return to everyday activities and independence. It includes supervised exercise, lifestyle education, psycho-educative therapy, and counselling by psychologists, dietitians, and social workers [43]. To increase participation and adherence, telehealth and eHealth approaches now enable home-based CR [108]. Effective CR interventions should be personalized to fit patient characteristics, specific conditions, and individual rehabilitation goals [80]. This encompasses considering disease and patient characteristics and personal rehabilitation goals [19, 24]. Since CTR uses communication and monitoring technologies, user-centred methods are essential to optimize interactions between remote care and their users [72, 75].

2.1.2 Athletes In and Outside CTR. Recreational athletes, or simply "athletes" (as referred to in clinical literature), are highly active individuals who engage in at least 4 hours of exercise weekly and may participate in competitions (e.g., cycling, triathlon, marathon) recreationally [68]. These athletes are driven primarily by enjoyment and sometimes competition, valuing the sensory and emotional aspects of their sport and often using performance-tracking tools to enhance their connection to the sport [105]. While physical activity lowers CVD risk, athletes are not immune to developing CAD [1, 69]. In a largely sedentary population, combating inactive lifestyles and instilling healthy habits are central objectives in (tele)rehabilitation [54, 57, 79, 111]. Nonetheless, CTR has the potential to provide sport-specific rehabilitation, allowing athletes with CAD to train at home with remote clinical oversight [114]. Limited studies indicate that hospital-based CR often fails to meet athletes' needs [45, 47, 92, 109, 114], as they prefer training in familiar environments with professional guidance essential due to exercise restrictions such as heart rate (HR) limitations or adjustments to the current structure of sporting activities [68, 78]. Previous work underlines the substantial psychological distress in athletic adults with cardiac conditions caused by exercise limitations [64]. Personalized clinical guidance and family support are essential as athletes often strive to regain former fitness levels tied to their identity [45] . However, differing goals between athletes and caregivers can create challenges [64, 114]. Limited research explores caregiver support for athletes in CR, though studies on healthy athletes show difficulties in balancing family life with sports [5], with partners sometimes being absent, overly supportive, or conflicted about the time athletes dedicate to their training [36]. Our work aims to expand the limited knowledge on relational dynamics between families and athletes, specifically around interactions with health data and information in CTR.

2.2 Patients and Informal Caregivers in C(T)R

2.2.1 The Dyadic Relationship in Cardiac Illness. Before evaluating caregivers' data access in CTR, it is essential to understand how individual and dyadic dynamics shape caregiving. As Nikkhah et al. argue, CSCW design must first identify interrelational mechanisms to design for them meaningfully [74]. Conditions like CVD disrupt support systems [16], making informal caregivers essential in decision-making and emotional support as illness becomes a shared experience [7, 15]. Two theories frame this collaboration: the Theory of Dyadic Illness Management [53] and the Model of Dyadic Coping [7, 15].

The Theory of Dyadic Illness Management views the patient-caregiver pair as interdependent, managing tasks like treatment adherence and symptom monitoring through shared appraisal [53]. This mutual process shapes both partners' health outcomes over time. In heart failure, equal collaboration has been linked to reduced depression and improved illness management [66]. The theory also accounts for contextual factors such as illness stage, relationship type, and support availability.

The Model of Dyadic Coping focuses on how partners respond to stress – illness-related or otherwise – through interdependent emotional and behavioural responses [40]. Caregiver anxiety, for instance, has been shown to affect patient well-being [17]. Coping processes include communication, mutual support (e.g., problem-focused or collaborative), and stress regulation to maintain relationship quality [7]. However, coping can also become dysfunctional – e.g., overprotection or communication breakdowns – as described in studies on CVD dyads [33, 86].

In practice, dyadic appraisal, coping, and management often overlap. Rapelli et al. [87] found that coping strategies can at times hinder self-management. Still, a consistent recommendation across studies is to involve informal caregivers – not just patients – in interventions to support shared illness navigation [84]. While CR typically centres the patient, emerging work calls for expanding its scope to include caregivers [17]. As CR shifts from hospital to home, caregiver involvement becomes increasingly vital. We adopt this dyadic paradigm as a foundation for designing CTR systems that support shared responsibility and coordinated care [7].

2.2.2 Integrating Dyadic Coping and Management with CSCW Boundary Theories. Theories of dyadic coping and dyadic illness management emphasise that illness is not experienced or managed in isolation but through interdependent processes of appraisal, communication, and shared action between patients and their close partners. In CSCW, such relational management of health aligns with the concept of boundary objects – artefacts that support cooperation across social worlds by allowing for interpretive flexibility while maintaining shared structure [100]. In caregiver–patient dyads, shared data artefacts like health dashboards or symptom logs can serve as boundary-negotiating artefacts, helping bridge epistemic gaps between parties – much like in broader healthcare contexts where such tools have been shown to support collaboration, as expanded by Chung et al. [29]. Our work builds on these concepts by illustrating how co-participation tools in CTR are not just information artefacts but relational infrastructures that must facilitate ongoing negotiation of boundaries, values, and roles. Bhat et al. [10] similarly emphasise how sociocultural dynamics shape the use and meaning of health data in familial caregiving, reinforcing the need for context-sensitive designs that support not only individual use but also interpersonal alignment and tension management.

2.2.3 Representation of Informal Caregivers in CTR and CSCW. CTR systems support information exchange between patients and clinicians in remote or hybrid CR, aiding clinical decisions and patient self-management [75]. Traditionally, patient-facing systems have focused on the patient as the sole user [59, 81], allowing them to track health via digital platforms, sensors, and surveys [72]. However, recent CSCW and HCI research highlights the caregivers' growing role in data interaction mechanisms. Bhat et al. discuss the caregivers' critical function as boundary actors in managing chronic illness, including cardiac, arguing for shared health-tracking responsibilities [10]. Their earlier research also highlighted caregivers' role in collaborative online information-seeking, which helps the dyad cope with illness [11]. Andersen et al. explore user experiences with a cardiac patient monitoring app, describing caregivers assuming the patient's role for symptom reporting [2]. They highlight the importance of co-experience in addressing the interpersonal aspects of remote care in health technologies. Similarly, El-Dassouki et al. noted off-label dyadic uses of digital symptom tracking in heart failure [37]. In later work, Andersen et al. describe how chronic heart patients and caregivers share and interpret wearable data together, urging HCI practitioners to design for relational and situational contexts in chronic disease management [3]. Recent research on patients with a left ventricular assist device during CR also shows joint symptom appraisal and monitoring with caregivers [77, 88]. Murnane et al. discuss how jointly appraising personal data can alleviate self-management stress, calling for *more research on supporting information sharing and data access in the social context of health management* [73].

This body of work highlights that managing chronic illness is not solely individual; it is deeply embedded in social relationships. It advocates shifting from patient-centric to ecological perspectives, where close social ties *co-participate* in technology-mediated health management. We define 'co-participation' from a data interaction standpoint, with caregivers accessing and monitoring patient data, using informational resources, and communicating with clinicians. It formalises the caregiver's role, granting rights tailored to caregiving. Growing design knowledge supports adopting this paradigm, as seen in co-participation systems for parent caregivers and children with diabetes (e.g., [25, 26, 55]) or other chronic conditions (e.g., [83, 94]), or adult dyads that deal with Parkinson's (e.g.,[76]), life after bariatric surgery (e.g., [51, 63]), cancer (e.g., [27, 110]), or epilepsy (e.g., [71]). In cardiac care, interventions often focus on heart failure patients and caregivers [62], offering caregiver access to clinician follow-up notes and recommendations (e.g., [82]), and shared emotional logging within the dyad (e.g., [107]). Although rare, CTR platforms allowing caregiver co-participation are mainly found in hybrid CR programs, providing caregiver access to the patient's rehabilitation plan, cardiac information, collaborative goal setting, activity data, and digital communication tools for patient-caregiver interaction [35, 113].

Implementing dyadic C(T)R has shown positive clinical effects on patient and dyad health outcomes, reinforcing the need to formalize the caregivers' role. However, the *design rationales* behind the development of these systems and *potential drawbacks* remain underexplored, such as the risk of caregivers becoming overprotective with too much data access [35]. Despite extensive research, CTR remains under-implemented [101], and existing patient-centric CTR interventions rarely integrate user-centred studies or design processes [85]. When user feedback is considered, it generally focuses *solely on patients*, excluding caregivers from both design and evaluation phases. This highlights *a lack of design guidelines* for effective co-participation in CTR. Furthermore, while CSCW has increasingly engaged with caregiving [26, 28, 55, 76], research on lifestyle rehabilitation technologies remains limited – where rather than long-term self-management the goal is recovery and preparation for a return to normalcy, pursued through a time-sensitive, intensive program [103]. This study addresses these gaps by employing user-centred methods to understand the key do's and don't's of caregiver co-participation, offering design recommendations for future dyadic CTR systems and the broader context of technology-mediated care.

3 Methodology

We outline our methodology for exploring caregivers' perspectives on the benefits and trade-offs of data and information co-participation in the context of CTR for recreational athletes.

3.1 Study Participants

Our study participants were caregivers of recreational athletes who had completed a CR programme within the year prior to recruitment. Athletes were eligible if they engaged in a sport for at least four hours per week, restricting the sample size to 17 athletes fitting the inclusion criteria. Of the 17 eligible athletes, 15 agreed to the experimental setup. To recruit caregivers, a clinician asked each athlete to identify the individual who had served as their closest support system during CR. With the athletes' consent, the caregivers they nominated were then approached, provided with the study information, and invited to participate. In total, 12 caregivers agreed to participate, out of which 2 only agreed to short phone interviews, limiting the use of scenarios. In the end, 10 caregivers agreed to attend the full interview, provided informed consent and were invited to participate in our study: 8 spouses (living in the same house as the patient), one mother of the patient, and one sister-in-law (living at different addresses from the patient) (Table 1). Caregivers residing with the patient lived with or without children. Caregivers living apart from the patient were caregivers of a patient living alone. While the living arrangements of the first 8 participants differed from those of the last two participants, we found that the responses of the two groups regarding data co-participation did not significantly deviate from each other.

Table 1. Participants (Informal Caregivers) Demographics

ID	**Gender**	**Age**	**Caregiver information**	**Relationship information**	**Athlete information**
IC1	W	30	Hairstylist; working	Dating athlete for 13 years; live together; pets and no children	Finished CR 6 months before study; practices mountain-biking, running, boxing, fitness
IC2	W	70	Teacher; retired	Married to athlete for 45 years; live together away from children	Finished CR 11 month before study; practices table tennis, cycling
IC3	W	71	Secretary; retired, volunteering	Married to athlete for 55 years; live together; no children	Finished CR 6 months before study; practices tennis, cycling, fitness
IC4	W	67	Complaint officer; retired	Married to athlete; live together away from children	Finished CR 15 months before study; practices running (marathons, ex-ultra marathon runner), cycling
IC5	W	52	Physiotherapist; working	Married to athlete; live together with child	Finished CR 12 months before study; practices running, high-intensity training
IC6	M	72	Metal worker; retired and volunteering; also cardiac patient	Married to athlete for 45 years; live together away from children	Finished CR 6 months before study; practices cardio/strength training, spinning
IC7	W	52	Secretary; working	Married to athlete for 28 years; live together with child	Finished CR 8 months before study; practices mountain bike, spinning
IC8	W	68	Healthcare worker; retired	Married to athlete for 40 years; live together away from child	Finished CR 10 months before study; practices cycling
IC9	W	66	Sales worker; retired; also cardiac patient with cardiac husband	Sister-in-law of athlete for 19 years; live separately	Finished CR 8 months before study (not referred to exercise training); practices fitness, cardio, high-intensity training
IC10	W	70	Managing own company; retired	Mother of athlete; live separately; caretaker of athlete before cardiac diagnosis due to athlete's hearing impairment	Finished CR 6 months before study; practices strength training, cycling

3.2 Study Procedure

This research has been conducted in a Dutch teaching hospital (Máxima Medical Centre Veldhoven) that offers both in-hospital CR and CTR (without formalised caregiver roles). The study used individual, face-to-face, semi-structured interviews lasting 60-70 minutes each. Participants were first asked for demographic information, including age, occupation, relationship to the patient, and living arrangement. In the first part, they discussed their caregiving relationship (including a survey), experiences with the athlete's rehabilitation, and coping strategies for safe sports resumption. In the second part, participants received an introduction to CTR and dyadic CTR technology. CTR is not yet a well-established care pathway in the collaborating hospital, and all athletes have participated in hospital-based CR. They then discussed their perceptions on six visual scenarios illustrating data and information co-participation. All interviews were audio-recorded with consent. One interview was in English; the rest were conducted in Dutch.

3.2.1 Survey Design. To better understand their caregiving role, caregivers completed a brief, five-minute survey detailing the type of support provided during rehabilitation. The survey's first question, based on Buck et al.'s dyadic typology [20], asked participants to select the dyad type that best described their relationship with the patient: *patient-oriented dyad* (patient performs most of the health management activities), *collaborative dyad* (with patients and caregivers splitting health management 50/50), *complementary dyad* (with patients and caregivers having non-intersecting spheres for health management), and *caregivers-oriented dyad* (with caregivers performing most of the health management). The second question concerned the types of caregiving activities they assisted patients with during rehabilitation split into the five categories described by Bidenko et al. [12]: *personal care* (e.g., bathing, dressing, mobility), *medical care* (e.g., taking medicine, blood pressure measurements), *household assistance* (e.g., shopping, laundry, meal preparation), *organizational support* (e.g., making doctor appointments, ordering medication), and *supervision and social support* (e.g., looking after the patient, keeping them company, providing moral support).

3.2.2 Semi-structured Interviews. After completing the survey, participants discussed their relationship with the athlete, their role in the athlete's sports and CR journey, and coping mechanisms related to safe exercise resumption and health management, including data-sharing practices and technology use. They were then introduced to CTR in the form of an athlete (Peter) recovering from a heart attack and engaging in a virtual CR program on a digital platform, where he can share sports and well-being data with clinicians and receive tailored recommendations. Peter's caregiver (Clara) also has access to monitor and interact with this data. Visual scenarios were presented one by one to explore how such data access might impact the dyad's dynamic. Participants were asked to describe what they liked and disliked about each scenario, with relation to their coping strategies. The resulting themes are discussed in the Results section.

3.3 Visual Scenarios of Co-participation

We designed visual scenarios to represent data and information co-participation functionalities and interactions in CTR centred around safe sports resumption for athletes. We draw inspiration from cards as a method to provide concepts (i.e., interaction with features) for specific design domains (i.e., dyadic CTR) [49]. Nonetheless, instead of the classic card design, we utilize text and images in a scenario-based approach to demonstrate interaction complexity and aid participants in envisioning the use of such functionalities within the context of athlete rehabilitation (Figures 1 and 2) [6].

Scenarios are a well-established user-centered design method that present fictional situations to help users envision future systems [13, 14, 91]. Since CTR is not yet common in the Dutch healthcare system and caregiver roles remain informal, we used scenarios to prompt caregivers to imagine their possible involvement. We combined activity scenarios (describing caregiver actions supported by a dyadic CTR system) and interaction scenarios (illustrating system behaviours) [91]. Inspired by previous HCI studies [89, 112], we integrated sketches alongside each scene to enhance clarity [38] (Figures 1 and 2).

Each visual representation illustrates the interaction with a CTR platform that formalises the caregiver's role as an active participant in the patient's remote care, additionally aiming to integrate caregivers into the athlete-clinician communication loop as engaged contributors. We first extracted key co-participation functionalities from C(T)R interventions described in literature [35, 113], patient-centric CTR (e.g., [46, 85]), or dyadic hospital-based CR interventions [62], and distilled them into six key interactions (e.g., experiential data sharing, collaborative goal setting). The first two authors adapted the identified interactions and functionalities to the needs of athletes in CR (e.g., clinical recommendations translate to sports limitations based on maximum HR). The resulting interactions were then validated with the rest of the research team. Subsequently, based on the theories of dyadic coping and illness management, we distilled positive principles such as bi-directional communication, transparency, setting limits for wanted support, collaboration, and mutual understanding [40, 53]. We then iteratively and collaboratively created textual versions of the scenarios for each interaction, following the identified positive dyadic coping and management principles. Lastly, we developed sketches for each scene depicting the two characters (Peter and Clara) and their environment, where needed (home, park). The full research team validated the final scenarios before use.

The six resulting visual scenarios represent the following interactions:

1) *Experiential data co-participation.* Experiential data capturing patients' anxieties and subjective experiences is increasingly used in CTR to enrich patient-clinician communication with meaningful insights (e.g., [102, 115]). This scenario includes caregivers in experiential data sharing via a mobile app featuring a daily diary. The app prompts both athlete and caregiver to log feelings and stress-related emotions and encourages shared entries – either within the app or in person. Users are notified when an entry is shared and can specify if they wish to handle a stressor independently or seek support. The app also facilitates positive exchanges; for instance, Peter expresses gratitude to Clara: "Thank you for your support; you're a fantastic partner/friend!" Both can also share concerns with a clinician through the platform (Figure 1).
2) *Sport goal co-participation.* Goal-setting is a common feature in CTR interfaces, enabling clinicians and patients to collaboratively establish appropriate health goals for the patient's unique recovery journey (e.g., [8, 35]). In our storyboard, we illustrate a scenario where the technology encourages the athlete to involve the caregiver in goal-setting or to share established goals and ambitions with the caregiver through the system (Figure 2).
3) *Access to (live) exercise data.* Physical activity is a central component of CR programs [104]. CTR systems record patient exercise data, sometimes transmitting it live or asynchronously to clinicians [85]. In the case of athletes, we drew a scenario in which the athlete can share live performance data such as location or HR while practising sports remotely (Figure 2).
4) *Co-monitoring symptoms.* Patients' subjective symptom perceptions are frequently collected via telemonitoring to support shared patient-clinician interpretation (e.g., [58]). In our scenario, we designed an option for the caregiver to contribute by reporting patient symptoms directly to the clinician through their own interface (Figure 2).
5) *Access to alarming signals in data.* Some CTR systems alert users when biophysical data, especially HR, exceeds safe limits (e.g., [46]). Athletes may receive exercise restrictions to prevent adverse events (e.g., a maximum HR). In our scenario, athletes receive alerts if they

Fig. 1. Storyboard number 1 depicting a scenario in which caregivers and athletes can log experiential data in the CTR system, share this data with each other, and give feedback to each other.

exceed these limits during exercise and are encouraged to share the alert with their caregivers. The system also suggests a course of action (Figure 2).

(6) *Access to clinical recommendations and information.* CTR platforms often include personalized clinical recommendations for health behaviours and information on cardiac conditions and lifestyle adjustments [85]. In this scenario, the caregiver has access to personalised clinical guidelines for safe sports directed toward the athlete and information resources (e.g., on caring for athletes with heart conditions) (Figure 2).

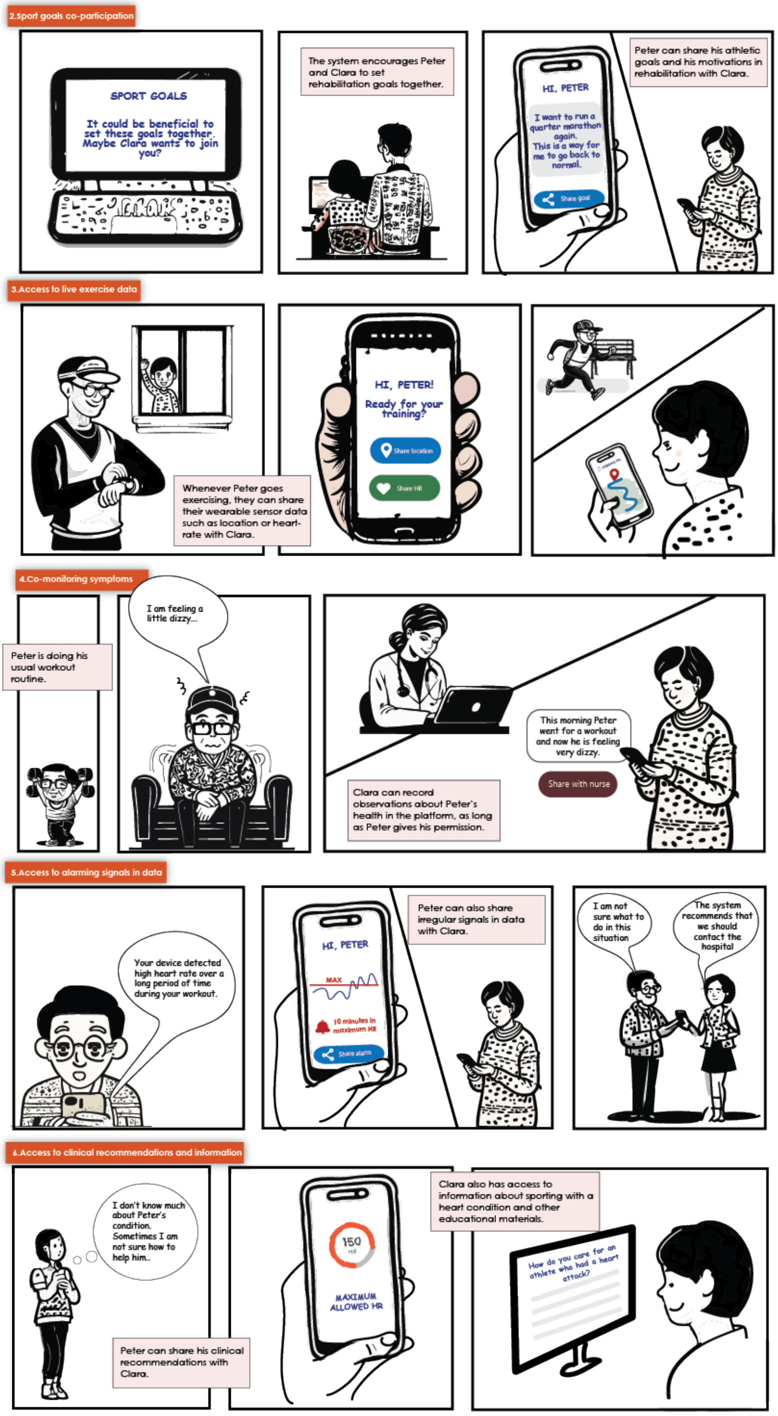

Fig. 2. Storyboards number 2-6 depict scenarios in which caregivers co-participate with various types of data and information in a CTR context.

3.4 Data Analysis

All interview audio recordings were transcribed verbatim, and nine were translated into English. We conducted a two-phase thematic analysis using a hybrid approach – combining inductive and deductive coding – to explore caregivers' perceived values and corresponding challenges of co-participation in cardiac telerehabilitation (CTR) [18].

Firstly, we used open inductive coding to examine caregivers' descriptions of existing relationship dynamics and coping strategies (e.g., 'anxiety related to athlete pushing oneself'). This yielded 18 codes, which we grouped into four overarching themes that characterise the caregiver-athlete relationship: (1) diagnosis and CR program recollections, (2) levels of caregiver assistance, (3) anxieties and worries, and (4) existing coping mechanisms. We present (1) and (2) in depth alongside survey findings to provide relational context for interpreting caregivers' perspectives on CTR. We use (3) and (4) to contextualise these perspectives in subsequent result subsections.

Secondly, for each scenario, we inductively coded perceived values (e.g., 'co-monitoring to be the voice of the patient') and trade-offs of co-participation (e.g., 'confusion related to data errors'), resulting in a total of 71 codes. We maintained the link between value codes and trade-off codes in our codebook, according to the interviews. These were grouped into five thematic clusters, starting with the perceived values (e.g., 'inclusion through ongoing visibility') and then deriving the perceived trade-off (e.g., 'too much visibility – unintentional supervision'). For example, the cluster about uncertainty at a distance versus distrust-fuelled vigilance contains 7 value codes such as 'reassurance that athlete reaches home' and 7 trade-off codes such as 'data not actionable in moments of crisis'. One additional theme resulted without corresponding trade-offs (i.e., 'emotional support for the caregiver').

After this inductive process, we applied Badr's and Lyons' Dyadic Coping and Illness Management [7, 53] frameworks as a deductive lens to organise our results into two overarching themes: health management and emotional coping. These frameworks helped us interpret and explain caregivers' perspectives through the lens of shared health work, alignment, and negotiation, which resonate with core CSCW concepts related to technology-mediated care such as collaboration, boundary work, and joint coordination [42]. Although the inductively derived theme related to external help-seeking aligns with both practical management and coping, we present it separately in this paper due to its distinct implications for technology-mediated care beyond the dyad. Further in Discussion, we relate our findings to CSCW concepts such as common information spaces, selective visibility and emotional labour, framing co-participation in CTR as a process shaped by both technological design and relational context.

We include an overview of the final themes and subthemes (Table 2), and a schematic of our guiding theoretical framework (Figure 3).

3.5 Research Team and Considerations

To conduct this research and ensure its validity, the research team consisted of HCI researchers and clinicians. An HCI researcher whose work focuses on health technologies (IBȘ) and a sports physician in training conducting research in CR and sports cardiology (LF) from the Netherlands conceptualised, planned, and conducted the study together. The hospital's medical ethical committee reviewed the study protocol, and a waiver was received stating that ethical approval was not required. The study was approved by the local committees of both Máxima Medical Centre and Eindhoven University of Technology.

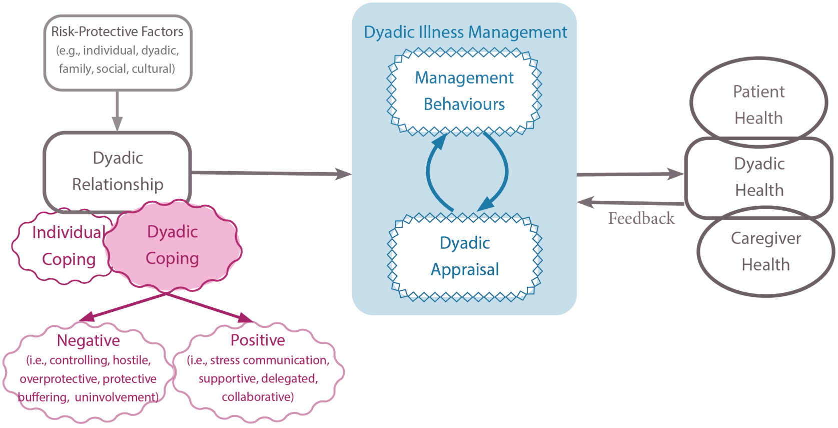

Fig. 3. Overview of the guiding theoretical framework for our data analysis, inspired by the works of Lyons et al. [53], Badr et al. [7] and Falconier et al. [40]. A similar model has been used in the work of Yang et al. [113].

Table 2. Overview of themes and subthemes, and connections to the Theories of Dyadic Coping and Management. Perceived advantages/values of co-participation are *italic*, while trade-offs are **bold**.

Thematic cluster	Subthemes	In Section(s)	Theoretical Concept(s)
The Caregiver-Athlete Relationship	Diagnosis and CR recollections	Section 4.1	Dyadic Relationship (incl. existing Coping and Management)
	Levels of caregiver assistance	Section 4.1	
	Anxieties and worries	Sections 4.2, 4.3, 4.4	
	Existing coping mechanisms	Sections 4.2, 4.3, 4.4	
Balancing Collaboration with Overextension	*Inclusion through Ongoing Visibility* vs. **Unintended Supervision** *Co-management through Collaborative Reflection and Shared Decisions* vs. **Undermining Mutual Autonomy**	Section 4.2	Dyadic Illness Management (Appraisal and Management Behaviours)
Balancing Support with Emotional Adaptation	*Managing Uncertainty at a Distance* vs. **Distrust-fuelled Vigilance** *Tackling Changed Relational Dynamics* vs. **Disrupted Relational Authenticity** *Individual Emotional Coping* (no specified trade-off)	Section 4.3	Dyadic Coping (incl. Individual Coping)
Balancing Help-Seeking with Health Ownership	*Caregiver Escalation* vs. **Health Ownership**	Section 4.4	Dyadic Coping and Illness Management

3.6 Method Limitations

Our participants were predominantly Dutch, Caucasian and women (9 out of 10 caregivers), limiting experiential diversity. Our sample size was restricted by the inclusion criteria and our patient subpopulation. We recruited caregivers within a year of CR completion to capture fresh experiences before recovery challenges gave way to long-term routine and management. While no studies estimate the proportion of athletes in CR, research highlights their distinct needs [45, 114]. Given athletes' sporting ability and C(T)R's emphasis on physical activity, we aimed to explore the unique caregiving dynamics in this context. Although small, our sample's consistency in experience allowed us to identify shared perspectives on CTR co-participation. The limited diversity in family structures and living arrangements (only two caregivers were non-spouses) restricted insights into household composition effects. Additionally, two caregivers (IC6 and IC9) were cardiac patients, meaning our sample may reflect greater familiarity with cardiac care than typical caregivers.

We interviewed caregivers independently to capture unfiltered perspectives, avoiding the potential influence of athletes' assertiveness [45, 114]. Moreover, most studies on technology-mediated CR prioritise patient perspectives, often treating caregivers as secondary participants that support patient perspectives [82, 107]. Our study instead foregrounded caregivers' opinions on the role of co-participation in their caregiving. The survey on caregiver roles and dyadic relationships helped contextualise their perspectives by examining how they position themselves within the relationship, define their responsibilities, and establish personal boundaries in co-participation.

Finally, our study was conducted in the Netherlands, where CR services are reimbursed under a GP-led private healthcare system. While ensuring broad access to CR, this model may differ from systems elsewhere, potentially shaping caregiver engagement in ways that limit generalizability.

4 Results

Caregivers in our study navigated CTR co-participation as a balance between support and autonomy, weighing the benefits of increased involvement against the risk of overstepping boundaries or adding burden to their role. As described in Table 2, in section 4.1 we first present the caregivers' perspectives on their evolving care dynamic in CR as a foundation for the following sections. In sections 4.2, 4.3 and 4.4 we examine caregivers' views on CTR participation, using Dyadic Coping and Management as a guiding framework to explore the perceived value of a formalized caregiver role and access to patient data: (1) dyadic illness management through appraisal with the help of increased visibility and health management based on shared decisions, (2) dyadic emotional coping through adaptation and support, and (3) a mix of both coping and management through clinician outreach. For these sections, we also present highlighted trade-offs, such as becoming unintentional supervisors, undermining mutual autonomy, developing distrust-fuelled vigilance and relational dissonance, and violating athlete health ownership.

4.1 Caregiver's Relational Role in CR as Context for Co-Participation

For all caregivers, the athlete's cardiac diagnosis marked a turning point, altering routines and introducing new forms of involvement in health management. While four caregivers were satisfied with clinical support during cardiac rehabilitation (CR), six identified gaps in program accessibility, personalisation, and follow-up care, particularly for athletic patients. These limitations left caregivers navigating uncertainty about their role, balancing *support with respect for the athlete's autonomy*.

Although caregivers viewed athletes as independent and self-sufficient, their involvement shifted throughout recovery. During hospitalisation and early CR, they engaged in *hands-on, collaborative care*, managing daily tasks and medical responsibilities. As athletes recovered, caregivers transitioned into a *supportive role*, offering encouragement, companionship, and occasional logistical help (e.g., appointments, clinician contact, symptom monitoring). IC10, for instance, facilitated calls due to the athlete's hearing loss. Across all dyads, caregivers emphasised that athletes remained the primary decision-makers in their care, a dynamic they sought to uphold despite their own concerns.

A defining feature of these relationships was *the centrality of sport*, shaping both identity and rehabilitation expectations. All caregivers respected the athlete's deep connection to physical activity and drive to resume training. Yet, this shared understanding did not eliminate tensions – particularly around defining safe exertion. While they avoided interference with sport routines

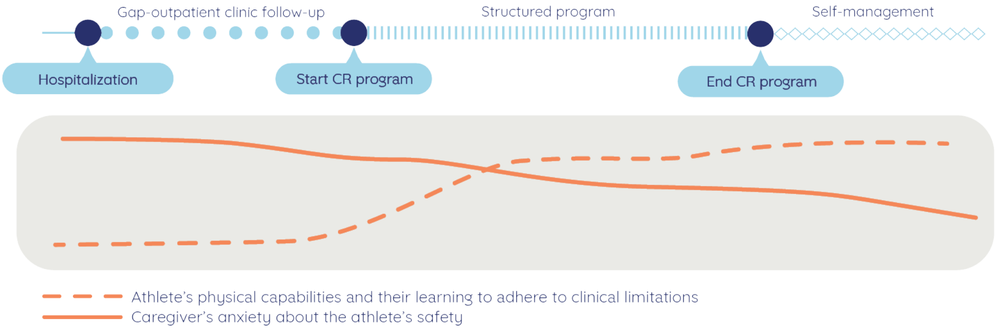

Fig. 4. All caregivers describe that, as the athletes regain their athletic capabilities, towards the middle of the program, there is a need to let go of the anxiety that "something bad might happen" and return to normalcy.

before diagnosis, several caregivers felt compelled to set limits or raise concerns about pacing and workload during recovery.

> IC3: "I said: 'I don't mind that [i.e., training] so much, but no longer, because you don't know how further you can go. You shouldn't overdo it.' But he did."

While our sample does not support definitive conclusions, caregiver involvement appeared to vary with relationship dynamics. Spouses (IC1–8) more frequently described engaging in daily conversations about training or voicing concern about overexertion, while the two non-cohabiting caregivers (IC9 and IC10) viewed pushing physical boundaries as key to recovery. Despite these variations, all participants consistently highlighted the need for caution around overexercising, suggesting it as a recurring concern. Some caregivers occasionally joined the athlete in lower-intensity workouts for companionship.

Across dyads, caregivers described a gradual return to pre-diagnosis relational norms, though with changes in communication and emotional expression. While athletes remained in charge of their recovery, caregivers noted that *health, training, and lifestyle* became more integrated into everyday conversation, not as sources of conflict, but as ongoing threads in the evolving relationship.

> IC5: "He often walks during the week, then I'm already working so I don't think about it. But on weekends, I do ask: 'Which route are you walking?'. That just creeps in because I think: 'Is he already home?' I subconsciously keep an eye on it."

Ultimately, caregivers saw their role as *balancing support with restraint*, offering encouragement without imposing pressure, surveillance, or control. Though minimally involved in medical decisions, their presence provided reassurance, validation, and adaptable support that shaped the rehabilitation journey.

4.2 Navigating Health Management: Balancing Collaboration with Overextension

Caregivers understood co-participation not merely as data access, but as a way to *negotiate visibility and involvement* in the athlete's rehabilitation. They sought to support without role overextension – respecting the athlete's autonomy while avoiding personal overburden. Across interviews, they expressed a need for adaptive strategies that enable flexible visibility and shared decision-making.

4.2.1 Seeking Inclusion Through Ongoing Visibility. While caregivers viewed athletes as independent and capable, they still expressed a desire for greater involvement and awareness during rehabilitation. Current engagement often relied on verbal updates or informal check-ins initiated by the caregiver. In seven dyads, athletes voluntarily shared progress by showing sports watches or mobile apps. Three caregivers also mentioned that athletes share measurements from medical devices, like blood pressure monitors.

> IC4:"I have a very general idea of: yes, it [i.e., sporting] went well or it didn't go well anymore. [...] I usually ask about it and then he shares it. He is in charge of the data and then he says 'This was my average and this was my highest speed and this was the lowest speed and I have walked so many kilometres and on that route'."

Despite existing practices, many caregivers felt that limited visibility created uncertainty and hindered meaningful involvement. Informal data sharing was appreciated, but caregivers preferred access to written clinical recommendations or sports goals to align expectations. Six participants indicated that knowing the athlete's goals in advance – such as target distances or planned effort levels – could help them feel more involved, reducing potential conflicts over athlete exhaustion. Still, many expressed a preference for high-level summaries or simplified signals as detailed metrics could exceed their technical comfort or interest – IC8 described how a blood pressure monitor's auditory feedback offered a reassuring, passive form of transparency.

Trade-off: ***Too much visibility could make caregivers unintended supervisors rather than partners.*** While caregivers appreciated ongoing access to general health data, many worried that excessive detail or constant updates could unintentionally turn them from supporters into monitors. Rather than fostering collaboration, this could create a sense of surveillance, undermining the athlete's autonomy and shifting the relational dynamic. Caregivers stressed that data should be shared intentionally and at the athlete's discretion to preserve trust and mutual respect. As IC9 explained: *"Not everyone likes others to have insight [...] The athlete does not want to be told that something is not good"*, reflecting a broader discomfort with the idea of assuming a corrective or policing role.

Some caregivers also noted they lacked the expertise or interest to interpret detailed metrics, reinforcing their preference for selective, high-level access over full visibility. IC7 articulately says: *"I think I can keep an eye on things, I think yes, but I am not his mother"*. This tension between reassurance and overreach shaped their ideal involvement: enough insight to feel confident, but not so much that it transferred control from the athlete onto them.

4.2.2 Co-Management in Practice Through Collaborative Reflection and Shared Decisions. Caregivers also viewed co-participation as a way to contribute meaningfully to health decision-making, particularly during uncertainty or symptom escalation. In contrast to passive access, caregivers described a form of collaborative reflection, where co-monitoring and alarms helped initiate conversations about appropriate next steps. For example, shared symptom logs or biometric anomalies, could allow caregivers to assist in interpreting whether to rest, monitor further, or contact a clinician. Access to system recommendations viewed as helpful aids in guiding such discussions.

> IC2: "They can discuss it together: 'Hey, I don't know what to do in this situation,' and you then say: 'The system thinks we should contact the doctor' that it is a kind of aid, also to support them, to actually talk about it together."

Some caregivers were already informally engaged in co-monitoring, such as tracking blood pressure or observing the athlete's physical and emotional state to inform clinical consultations. A few participants described situations where they acted as intermediaries – speaking on behalf of the athlete symptoms were dismissed. They saw co-participation tools as a means of enabling delegated support during moments when the athlete could not self-advocate. Others described collaboration in more routine or preventive ways, like co-setting goals, joining workouts, or researching health information together. These practices fostered shared understanding, mutual motivation, and emotional solidarity.

> IC2: "I think that's [i.e., setting goals together] a good idea, yes, that it's fun, that you do something together, tackle it together."

Across these accounts, caregivers emphasized that their motivation was not control, but meaningful collaboration – to be trusted partners in the recovery journey, informed enough to support while respecting the athlete's boundaries. As roles evolved, their involvement remained shaped by shifting dynamics of trust, safety, and perceived need.

Trade-off: *Unbounded co-management might undermine mutual autonomy.* While many caregivers saw value in co-monitoring and collaborative decision-making, several emphasized that if not appropriately bounded, such practices could inadvertently undermine the autonomy of both the athlete and themselves. On one hand, caregivers expressed a reluctance to interfere unless necessary. As IC7 explained, *"[the athlete] handles that very well, so I wouldn't do this"*, referring to having access to heart rate alarms that pose a need for further action. IC7 adds, *"Suppose he goes too far. Then he will know for the next time not to go that far"*. These reflections highlight the caregivers' confidence in the athlete's ability to learn through experience, suggesting that over-involvement could be not only unnecessary but counterproductive.

At the same time, caregivers also recognised the emotional and cognitive burden that could arise from taking on too much responsibility. After viewing all scenarios, IC2 mentions: *"It does ask a lot from the partner, doesn't it?"* The expectation to continually monitor, interpret, or act on system-generated insights risked creating stress and reducing their own sense of independence in daily life.

4.3 Navigating Emotional Coping: Balancing Support with Emotional Adaptation

CR affects not only athletes' physical recovery but also poses significant emotional challenges for caregivers. Participants shared how co-participation could help manage post-diagnosis anxiety and support the evolving emotional dynamics of the caregiver-athlete relationship. At the same time, they stressed the importance of preserving mutual trust, healthy engagement and existing relational authenticity.

4.3.1 Managing Uncertainty at a Distance through Just-in-Time Reassurance. The shift from supporting an independent, active person to becoming their primary caregiver after a heart diagnosis was described as overwhelming. All caregivers reported experiencing uncertainty and anxiety, particularly after hospitalization and during CR. Eight participants expressed heightened stress when not physically present with the athlete – such as when at work or running errands – fearing a sudden health event might occur without anyone to help.

> IC3: "I sometimes had some concerns about that, especially in the morning when he went into the woods early, that no one would come across him. I didn't really like that, but that hasn't been the case for a long time."

Caregivers also worried athletes might overexert themselves or train beyond their physical limits, especially when clinical recommendations about sports restrictions were not clear enough. These anxieties were eased when athletes exercised in the presence of others, such as at a gym or with a running club.

> IC7: "He quickly wanted to go cycling, and I was like, 'Yes, but I don't think you are allowed to do that at all; you are only allowed to walk around the block'. He says 'I'm

> going completely crazy'. [...] He is just used to always exercising, so he wanted to be on that bike again."

To alleviate these concerns, many caregivers turned to informal strategies: six participants mentioned communicating details like the workout area, route, and estimated duration or return time, while three reported meeting athletes along the route if they were late. Five participants already used live location tracking (e.g., via Strava), especially during CR. IC8, for instance, shared how tracking location helped her stay reassured:

> IC8: "I can trace him on my phone. Then I just keep an eye on him. If he stands still, you see it on your phone. He also says: 'I'll be gone for an hour or two hours and I'll keep that [cycling] going for a while'. It's not like I'm constantly looking at my phone."

These practices allowed caregivers to remain peripherally aware of the athlete's safety while preserving a sense of normalcy. They suggested a system where the athlete could indicate they are safe or share updates, helping to reduce anxiety and provide reassurance.

Trade-off: *Remote monitoring risks fostering distrust-fuelled vigilance.* While many caregivers appreciated temporary access to location or exercise data during workouts, several strongly opposed continuous tracking. Confidence in the athlete's internal compass was central, with three caregivers noting they already received sufficient verbal updates and trusted the athlete to follow medical guidance. As IC10 reflected, *"I think it damages his self-confidence because of the control. Shouldn't he experience that for himself?"*

Concerns also centred on protecting the athlete's independence, particularly in domains where they felt most competent – such as physical activity. IC4 questioned whether their partner would be comfortable with constant location sharing, remarking, *"These are all sensitive things for him"*. For these caregivers, autonomy was not just a value but a condition for recovery and trust.

In addition, participants shared the quiet expectation that things will be okay, even at a distance. They worried that constant monitoring could heighten their own anxiety and limit agency as data could be ambiguous, non-actionable, or even misleading, especially if athletes paused unexpectedly or socialized mid-workout. IC5 explained that seeing the athlete stand still on a map could be "false information" and warned against medicalizing everyday behaviour, adding, *"We shouldn't rely too much on devices"*. For some, the emotional toll of over-involvement was also a concern. The temptation to constantly check could lead to obsessive behaviours, as IC7 shared: *"If I have to keep track of all these things, then yes, I'll be watching all day. I don't really want that either."*

4.3.2 Tackling Changed Relational Dynamics By Building Emotional Connections. Beyond safety concerns, caregivers emphasised the importance of emotional coping as a shared process with the athlete. The cardiac event disrupted the relational dynamics – particularly communication. Several caregivers noted that athletes struggled with reconciling their athletic identity with a serious heart condition, leading to personality shifts and avoidant communication. This left caregivers feeling disconnected and unsure of how to offer support. Structured co-participation, such as sharing self-reported stressors, was seen as a valuable bridge for navigating these difficult conversations. For participants who found direct communication challenging, emotional logs or app-based reflections offered an alternative pathway to emotional support.

> IC3: "I throw it out there, but he is not that easy and he says: 'You know that I am not much of a talker'. But me, I just keep going, I just keep rattling on because it's so important to me. [. . .] Things could be different if we spoke more easily. [...] I think that [athlete's character] changed a little bit."

Nine caregivers acknowledged a lack of shared understanding about the importance of higher exercise intensity during rehabilitation. Conflicts often emerged from their own overprotection, especially when athletes overestimated their stamina and overexerted themselves, impacting home routines. Seven caregivers described negotiating such moments and expressed that access to training schedules, goals, clinical guidelines (e.g., safe intensity levels), but also aspirational goals (e.g., the need to feel normal again) would help them better contextualise the athlete's drive and facilitate more empathetic connections.

> IC1: "When he did the marathon, he got the green light, I think, two months before, so it was quite like a small time for him to practice. That's why I was also a bit sceptical. Is it not too soon? Did you practice enough? If not, all right. Stop. [...] I think what it says here [in the scenario], that he [the athlete] wants to be normal. Yeah, I can understand that, because that was for us as well. Like, if he can do that, he can do anything."

Six caregivers noted that access to shared goals and achievements not only fostered empathy but also enabled positive reinforcement. Seeing completed runs or milestones offered emotional reassurance and moments to celebrate together – particularly valuable for IC9, who lived apart from the athlete.

> IC9: "You could give someone extra encouragement [...] If the person is open about it and wants to share that, then you can support that person."

Trade-off: ***Formalized co-participation can disrupt relational authenticity.*** While caregivers acknowledged that digital tools could aid emotional sharing – particularly when conversations are difficult – they also expressed concern that over-reliance on technology-mediated care might erode the emotional fabric of the relationship and disturb well-established roles.

Several participants emphasised that spontaneous, verbal interactions were essential to maintaining genuine emotional connection. Structured emotional logs or prompts felt reductive or misaligned with their relational style. For many, emotional sharing already occurred naturally through in-person dialogue or casual messaging. As one caregiver put it, the richness of care lies in small, human gestures, not data points:

> IC4: "But this is the problem with all this digitalisation. I think it is very important that there is human contact and that does not have to be for hours, even if it's just for a moment [to tell the other]: 'oh, how bad, how annoying for you!' ''

Others were wary of tools that assumed bonding over aspirational goals or emotional reflections that did not match their relationship dynamic. Especially for caregivers with limited athletic backgrounds, engaging in sport aspirations felt unnecessary and unnatural. They preferred brief updates and chose to offer support from a respectful distance.

> IC7: "He did have a kind of schedule. He has been used to doing that for 40 years – what times he wants to run, how many kilometres he wants to run. [...] I think it is good to know [the athlete's goals]. Whether I should do anything with it is another matter. [...] In retrospect, I kept a lot of distance from it: yes, you are so autonomous, and you still do your own thing, and I have no influence on it."

These reflections highlight that empathy and encouragement are most meaningful when grounded in genuine conversation and spontaneous expression. While digital tools may help surface unspoken concerns, participants stressed that authentic emotional connection depends on preserving natural interaction.

4.3.3 Individual Emotional Coping: Extending Emotional Support to the Caregiver. While much of the emotional labour in CR focused on supporting the athlete, several caregivers reflected on the toll it took on their own well-being, often feeling their needs were sidelined. Five caregivers reported receiving little to no psychological or social support and expressed a desire for more structured mechanisms that acknowledged their role and provided them with emotional care. Formalizing the caregiver's presence in CTR – through self-reporting tools or mental health check-ins – was seen as a valuable way to manage emotional overwhelm and navigate shifting dynamics at home.

> IC4: "Maybe it's nice that someone says 'Yes, but, madam, how are you?' [...] It's all about the patient. And after a few weeks, you think, what about me? That's why I think it's a good thing that people at least try it with such an app [...] Someone might intervene and say: 'Is it a good idea for us to make an appointment to talk about it?"'

Beyond seeking professional support, caregivers saw emotional self-reporting as a valuable tool for self-reflection and communication. Documenting their experiences could help them process emotions, gain perspective, and share insights with family or fellow caregivers facing similar challenges.

> IC5: "You can write things off and put things into perspective. We are of course quite selective in what we remember [...] It can also be shared with third parties and perhaps even with children."

Participants' reflections suggest that emotional co-participation in CTR should encompass not only support for the athlete but also for the caregiver as a co-affected individual, whose well-being is integral to the dyad's recovery.

4.4 Beyond Dyadic Support: Balancing Help-Seeking with Health Ownership

While all caregivers highlighted the strength of mutual support, either emotional or practical, they acknowledged that dealing with the rehabilitation together is not always enough – especially during emotionally charged or high-stakes situations. In these moments, caregivers expressed a need for system-supported, individual access to clinical input, particularly when navigating recurring conflict, emotional distress, or uncertainty about the athlete's physical limits.

Participants envisioned co-participation tools as a means to surface unresolved emotional or medical concerns, using features like shared self-reporting to involve clinicians in monitoring relational dynamics. They also valued the option to escalate persistent disagreements – such as over training intensity – to a third party. For instance, IC4 described how repeated conflicts about workout safety could benefit from external mediation:

> IC4: "I think it's very easy to get into discussions that you can't resolve. [...] Peter seems of course in character, a bit like an extension of my partner: 'Yes, I'm going to do this today' and I think: 'Is this wise?' [...] The two of you cannot reach an agreement, you have known each other for 45 years [...] I think it would be very nice if there is a third party who does.[...] An expert, they come together to talk about it."

Participants emphasised that emotional proximity and long-standing relational dynamics can sometimes limit their ability to intervene effectively or persuade the athlete. In such moments, they valued the presence of a neutral, professional voice – even when prompted by system-supported data sharing – as a source of clarity and potential resolution.

Beyond conflict mediation, caregivers also wanted the ability to share symptoms or subjective observations with clinicians, particularly when the athlete felt unwell but was reluctant to act. IC4 described how professional input could offer both reassurance and clear next steps in times of uncertainty:

> IC4: "I think as soon as he doesn't feel well, then I will be on top of it and I would like it, that you would indeed have an expert look over it and you can ask whether or not this is something [...] If a professional said 'No, it's nothing, don't worry.' or 'Just drop by'. I would like that part of guidance, yes."

Across these accounts, caregivers expressed a consistent need for clinical scaffolding within co-participation, especially when their emotional resources or influence were not enough. Whether through escalation pathways, emotional check-ins, or third-party mediation, participants underlined that effective co-participation must include professional touchpoints—not just for athletes, but for caregivers as well.

Trade-off: ***Caregiver-initiated escalation risks violating athlete's health ownership.*** While caregivers expressed a desire for access to clinicians – particularly during moments of uncertainty or conflict – they also emphasized that such access should not come at the expense of the athlete's control over their health decisions. For many, sharing symptoms or concerns with clinicians was acceptable only when it supported the athlete's voice, not when it overrode it. Several caregivers stressed that any form of escalation should involve the athlete explicitly, in keeping with their relational values and mutual trust.

> IC8: "Yes, but I wouldn't do it behind his back. I would involve him and say, 'Is it okay if I indicate it this way?' I would do that, because when you go to the doctor, you forget everything."

Participants did not view co-participation as a license for unilateral clinician outreach but as a means to empower the dyad through mutual agreement. They valued logging tools and digital symptom sharing for aiding shared memory and building clarity ahead of clinical consultations. However, in high-stakes situations, caregivers expressed reluctance to rely on asynchronous channels. When symptoms seemed alarming, they preferred immediate phone calls over system-mediated responses, seeing direct contact as more practical and ethically sound – less likely to bypass the athlete's awareness or consent.

5 Discussion

5.1 Overview

This study addresses a gap in user-centered research on informal caregiver co-participation in cardiac telerehabilitation (CTR), and a broader absence in HCI and CSCW literature on how caregiver roles evolve in data-mediated rehabilitation systems – despite existing research on technology-supported caregiving in chronic care [10, 76, 83]. The focused, time-bound nature of rehabilitation introduces distinct relational and design challenges that remain understudied. We open this conversation by examining the perceived advantages and potential downsides of caregiver involvement in data and information sharing from the perspective of those supporting recreational athletes.

While caregiver support is critical for sports recovery [45], the unique dynamics shaped by both the athlete's and CR program's focus on physical activity remain understudied – despite their potential to offer valuable insights for CTR and CSCW caregiving system design. We used the Dyadic Coping [7, 15, 86] and Illness Management [53] theories as guiding frameworks to interpret our findings. These relational models, rooted in the shift from individual to shared coping, foreground the importance of caregivers in dealing with chronic conditions, a perspective often overlooked in CTR. They helped us identify mechanisms such as shared appraisal, emotional scaffolding, and risk-protective factors like personal values and relationship dynamics – key considerations for caregiver-inclusive design. Critically, these frameworks offer more than analytical clarity: they provide *application power*, offering CSCW researchers a structured lens for translating descriptive accounts of relational dynamics to actionable insights, bridging the gap between social theory and system design, as advocated in prior work on care infrastructures [42, 74].

Our work contributes to CSCW research by offering a unique perspective on co-participation in technology-mediated care, foregrounding the caregiver's role within a relationship grounded in mutual independence and shaped by identity shifts. Through scenario-based interviews, we show that co-participation goes beyond data access or task division – it involves navigating emotional labour, system expectations, and evolving relational boundaries towards detachment. Key findings suggest that CTR technologies should accommodate interrelational complexity and care value tensions by supporting: (1) adaptive, time-bound C(T)R co-participation, (2) caregiver role formalisation without overextension, (3) emotional coping that respects well-being and relational authenticity, and (4) pathways for escalation and caregiver mental health. We first frame these findings around CSCW themes of *extending caregiver-patient models*, *boundary work and negotiation*, *emotional labour*, and *adaptive care systems* while acknowledging that effective co-participation sometimes requires external support when dyadic coping falls short. We conclude with *design implications* for building caregiver-inclusive CTR interventions.

5.2 Extending Caregiver Co-participation Models

Prior HCI and CSCW work on caregiving has largely focused on fixed-hierarchy contexts, such as dementia care, parent-child health management, or long-term chronic condition management where caregivers act as primary coordinators and overseers [25, 26, 67, 98]. In contrast, our study examines co-participation within a dyadic relationship where independence and physical competence remain defining traits of the patient. Unlike in many chronic illness caregiving settings where the caregiver's role centres on ensuring patient adherence to medical regimens [52, 62], caregivers of athletes in CTR must navigate a relational dynamic rooted in trust and shifting involvement, reflecting CR's core principles as a co-constructed journey toward autonomy and return to normality for both the patient and their support system [79, 103]. Rehabilitation supports athletes in regaining control over their sport within safe limits [45], while caregivers rebuild trust, manage anxiety, and adapt through emotional regulation and reassurance.

Participants described caregiving as a transitional journey – initially *hands-on*, shifting to *'in-the-shadows'* support. This differs from caregiving models with static dependencies. Their role, often framed as 'temporary co-managers', required a balance between direct involvement and open communication, distant presence and respectful silence, and, occasionally, care for oneself outside the dyadic relationship. The implication is that caregiver involvement in CTR is not only *adaptive* but also *time-bound* and *co-constructed* with the athlete – something our participants highlighted consistently. This builds on CSCW research showing that caregiving is often a negotiated process rather than a fixed role. For example, Fitzpatrick and Ellingsen highlight how care involves continuous coordination and relational boundary-setting – the frame through which people set and maintain relational roles in care [42]; Pina et al. [83] and Buyuktur et al. [22] illustrate how independence and involvement are collaboratively managed in chronic care settings; and Schurgin et al. [93] emphasize how caregivers adapt their roles over time in response to evolving needs and relational expectations. However, our work distinguishes itself by focusing on a bounded rehabilitation period with **a built-in arc of increasing autonomy**, flipping the typical model of caregiving as linear or escalating. Here, caregivers learn to gradually let go (both practically and emotionally) rather than take over – calling for technologies that support release and trust-building, not just coordination or oversight.

5.3 Caregiver Co-Participation as Boundary Negotiation

Within the extended co-participation model described above, caregivers explain that boundaries around who participates in health management and relational coping, when, and to what extent are not static. With the introduction of technology-mediated CR care, these boundaries require even more active negotiation over time, as caregivers remain acutely aware of the potential risks that formalized data involvement could pose to autonomy, trust, and relational dynamics. These negotiations are complicated by tensions between **pre-existing, established values** – such as respect for autonomy and clearly defined roles – and **post-diagnosis needs**, including emotional reassurance and increased involvement in sport management. Such care value conflicts echo tensions documented in boundary work literature by Chung et al. [29] and Fitzpatrick [42]. We also offer a worked example that extends important work by Berry et al. [9], calling for technological support that can help partners cope with asymmetric values impacted by the trajectory of chronic illness, as these can disrupt dyadic collaboration.

Caregivers acknowledged that their cautious approaches, especially around sports, may clash with athletes' independence and CR ambitions [36, 65]. They desired access to sports data for better emotional coping but did not want to impose real-time monitoring on athletes. They wanted more visibility to perform better health co-management without becoming impersonal monitors. We extend the work of McDonald and Mentis on "respectful distance" claiming that technologies centring on transparency must also provide space for selective visibility [67]. Our participants valued data when it was contextual, consensual, and limited in duration.

However, such mechanisms do not always guarantee a balance between care values. Even well-intentioned design choices may unintentionally reinforce tensions if they fail to support nuanced, real-time negotiation and consent – e.g., the caregiver might be more anxious about safe exercise because of overly detailed data. As Burgess et al. [21] argue, care frictions are inevitable when care relationships are asymmetrical or involve conflicting emotional, informational, or power dynamics. In our case, caregivers often viewed athletes as having the upper hand – both in understanding what is best for their health and possessing greater knowledge about sports – reflecting a pre-existing power dynamic that persisted post-diagnosis. Hence, in dyadic CTR, such frictions may appear in the shape of negative dyadic coping mechanisms such as hostility (e.g., through the caregiver's silent anxiety), or protective buffering (e.g., caregivers choosing to suppress concerns to avoid undermining autonomy) [40]. The emergence of these tensions is not a design flaw but a reflection of complex interpersonal dynamics [21]. Systems must go beyond static boundary setting (e.g., fixed access permissions) to actively support *ongoing boundary negotiation* – even during moments of misalignment.

We contribute the concept of *negotiated co-participation* to describe the evolving, co-constructed nature of caregiver involvement in CTR, expanding CSCW's understanding of caregiver roles as co-calibrated rather than unilaterally defined. Building on Star and Griesemer's boundary objects [100] and Chung et al.'s boundary negotiating artefacts [29] – which show how patient-generated data mediate collaboration between patients and clinicians by enabling negotiation of roles, boundaries, and authority – we extend these ideas to caregiver–athlete dyads. In our study, features like dashboards, check-ins, or shared logs become situated tools for balancing visibility, emotional expression, and autonomy. We thus frame negotiated co-participation as **boundary work-in-practice**, where relational roles and care values are continuously negotiated through system use. This reframing calls for *adaptive, context-aware negotiation tools* that treat boundary management and value tensions as dynamic, situated processes (Figure 5), complementing ongoing work in collaborative health and family informatics [9, 74, 97].

5.4 Recognizing and Supporting Caregivers' Emotional Labour

We add to a growing body of CSCW literature that argues for the dual recognition of emotional labour in care technologies, such as Smriti et al.'s work [98], which sheds light on the emotional work of caregivers often taken for granted. We discover similar sentiments, where caregivers lack assurance, emotional connection, and clinical outreach that would offer peace of mind.

While dyadic collaboration was central, several caregivers described moments when internal coping fell short – especially during recurring conflict or emotional overwhelm. In these cases, they expressed a need for clinical or psychological escalation channels, such as sharing symptom

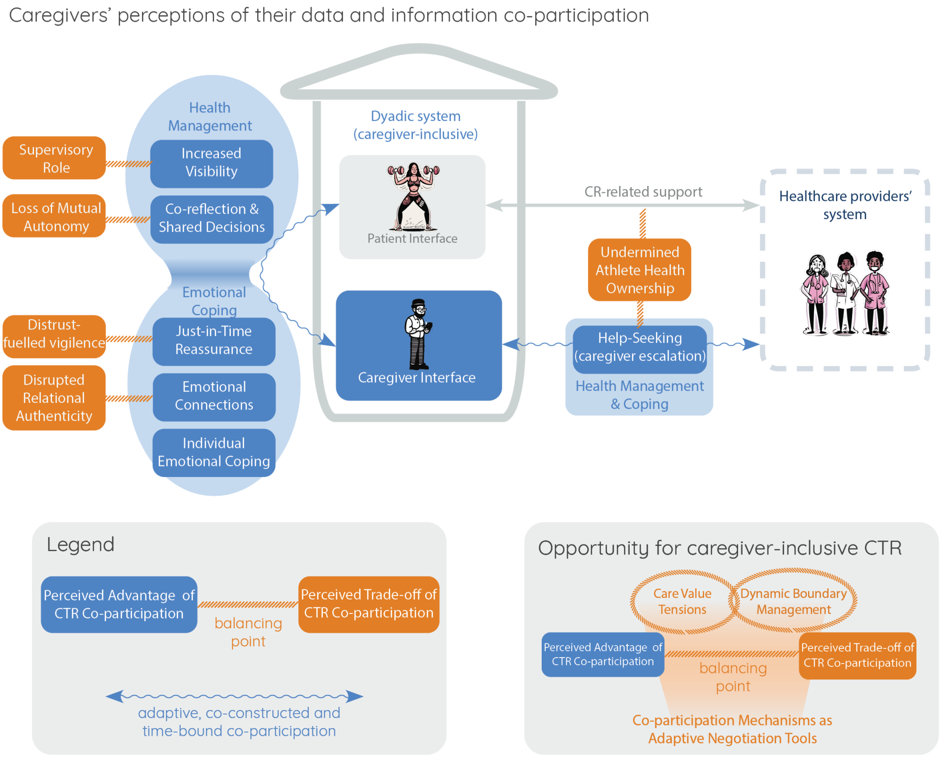

Fig. 5. Caregiver co-participation in CTR can enable both individual and dyadic coping benefits, but also poses risks when care value tensions arise. To maximise positive outcomes and minimise relational trade-offs, systems should support healthy boundary negotiation through adaptive, context-aware design.

logs or flagging emotional distress to professionals. These needs aimed not only to support the athlete but also to maintain peace of mind that help was available. Caregivers were cautious, however, highlighting that any such mechanism must respect the athlete's health ownership and be mutually agreed upon. This aligns with CSCW work on boundary negotiating artifacts, which shows how shared data must preserve autonomy and trust [99]. We offer a distinct perspective by surfacing the overlooked complexity of care escalation in systems centred on patient self-management. Collaborative health technologies should not only support intra-dyad care, but also *facilitate external scaffolding* when dyadic coping is not enough, without undermining relational trust.

Furthermore, a notable gap in current CSCW caregiving literature is the under-examination of emotional labour and caregiver mental health in dyadic systems [9, 55, 83]. Our participants reported persistent anxiety, particularly when athletes exercised independently. Yet, they hesitated to overstep, wary of disrupting the athlete's confidence and increasing their own anxiety through obsessive behaviours. Unlike in traditional caregiving settings, *emotional reassurance in CTR is intermittent and tied to moments of perceived risk*. Some caregivers expressed a desire for 'light-touch' monitoring – a periodic check-in or high-level overview – rather than continuous tracking. Others requested emotional self-report tools that could signal when psychological support is needed, not only for the athlete but also for themselves. CTR interventions should integrate caregivers' experiential knowledge into the design process, using approaches such as asset-based design that value caregivers' strategies, emotions, and boundaries as design materials [96].

5.5 Rethinking Technology-Mediated Care in CTR and Beyond

5.5.1 Conceptual Shifts in Designing for Dyadic Co-Participation. Bhat et al. [10] discuss balancing patient agency with caregiver support in chronic care, while Dinesen et al. [35] uncover caregivers' internal struggle between over involvement and equal partnership in CTR. Nonetheless, concrete strategies to address this balancing challenge are missing. Our study identifies similar frictions for caregivers of recreational athletes in CTR, yet questions remain about data access, control, and designing for these tensions. Based on identified co-participation advantages and trade-offs, we recommend designing dyadic CTR systems with bridging mechanisms that adapt technology to meet evolving care needs [23].To guide such shifts in designing caregiver co-participation mechanisms, we draw on frameworks such as Value Sensitive Design (VSD) [44] and Shilton's work [95] on participatory value identification in sociotechnical systems. These frameworks emphasize that technology should accommodate value tensions rather than obscure them – an insight especially critical in dyadic contexts where values like trust, independence, and safety may raise both internal and dyadic conflicts.

Building on our findings, this section outlines broader conceptual shifts needed to support dyadic co-participation in CTR. These shifts frame co-participation as *collaborative and context-sensitive* rather than fixed or hierarchical. Our findings call for a departure from static monitoring systems toward designs that reflect the evolving nature of caregiver involvement in CTR. Existing telerehabilitation platforms tend to assume consistent caregiver roles and patient passivity [62, 107, 113]. We reconceptualize CTR technologies as adaptive negotiation tools, not just monitoring systems. This shifts the design focus from compliance to collaboration, from fixed roles to flexible engagements.

To enable such caregiver engagement, CTR systems should embrace a range of conceptual design shifts. First, data sharing must be *selective and time-bound*. Rather than continuous monitoring, systems should offer adaptable visibility options following the principles of common information spaces [42]. Second, *reassurance should be low-burden* – technologies should discourage habitual surveillance, as seen in chronic care alert systems [70]. Third, systems should support joint decision-making by facilitating *boundary discussion* – an approach grounded in collaborative care frameworks [21] that offers the caregiver constructive visibility and appraisal. Finally, CTR technologies must recognize that *care frictions are inherent to dyadic care* and are not failures. Systems should make space for disagreement or emotional misalignment, drawing on work in CSCW that reframes non-compliance as a site of productive, critical reflection [21, 106].

5.5.2 Design Recommendations for Dyadic CTR Systems. Translating the conceptual priorities from subsection 5.5.1 into actionable strategies, we propose the following concrete recommendations for building caregiver-inclusive CTR systems. These design strategies reflect the realities of dyadic coping and adaptive care. Based on these insights, we propose design directions:

- **Formalise caregiver role without rigidifying it:** Recognise caregivers as legitimate stakeholders in CTR, with customizable participation modes, allowing them to have control over their own involvement. Some may only want major alerts, while others might prefer a more active role – this flexibility prevents overload and extends CSCW work on caregiver burden and autonomy by supporting nuanced data control in dynamic health contexts [10, 22, 39, 93]. Acknowledge that caregiver participation needs to be previously co-constructed and agreed upon with the patient.
- **Design for negotiated visibility:** Allow both caregivers and athletes to set, adjust, and review levels of data access based on evolving comfort and rehabilitation phases. This can include mechanisms like content-based sharing, temporary access permissions, or role-based

visibility settings [110]. As Cornejo et al. suggest, these boundaries work best when co-defined within the patient-carer relationship [31], ideally facilitated early on by a mediator such as a CR nurse.

- **Support emotional labour:** Support caregivers' emotional well-being through expressive communication tools (e.g., voice messages, video), mood tracking, and self-reporting to aid both personal coping and patient dialogue. Sharing emotions with peers or escalating concerns to clinicians can validate feelings and offer relief – extending Smriti et al.'s call for emotionally supportive mechanisms in chronic care contexts [98].
- **Enable context-aware alerts:** Replace caregivers' access to real-time monitoring with context-aware, event-based triggers that surface only meaningful deviations [102]. Periodic "I'm okay" check-ins, inactivity alerts, or establishing pre-defined safe zones can offer reassurance without undermining autonomy – enabling timely interventions while reducing information overload.
- **Promote co-reflection and co-regulation:** Foster shared understanding by enabling dyads to reflect on progress, goals, and emotions through trend summaries, shared journaling, and milestone celebrations – supporting collaboration without encouraging constant oversight, as seen in family care systems [83]. These tools should promote ongoing coordination through structured yet low-pressure feedback loops – what Koschmann et al. frame as "common ground" in cooperative reflection [60].
- **Accommodate misalignment:** Enable mechanisms to surface, negotiate, or defer emotional and informational disagreements, recognising that not all tensions require immediate resolution. CTR systems could offer conversation prompts, asynchronous communication tools, integration with familiar apps (e.g., WhatsApp, FaceTime), or escalation pathways. Culturally adaptive features – like symbolic emotional cues – can further support open dialogue when direct conversation is challenging, echoing Bhat et al.'s work on sociocultural dimensions of health tracking. [11].

Together, these recommendations expand how CSCW conceptualises and designs for informal caregiving in CTR. At the same time, dyadic coping and illness management theories offer both a vocabulary for describing relational dynamics and a framework for designing systems that promote positive patterns – such as collaborative problem-solving, mutual support, and adaptive role-sharing – while avoiding negative ones like overinvolvement or avoidant communication [7, 40]. Embedding these principles into system design helps technologies align with caregiver practices while fostering resilient, equitable relationships. Our study reinforces that caregiver involvement is not static but shaped by trust, emotional labour, and evolving boundaries. Designing for this fluid participation enables systems that better reflect the complexity and values of real-world caregiving.

6 Limitations and future work

Given our limited sample size, future research should include a wider and more diverse range of caregiver relationships (e.g., non-spousal, culturally diverse, or long-distance caregivers) to examine how co-participation preferences and tensions vary across contexts. Future work should also address the *gender imbalance* often seen in CR research, where men are typically patients and women caregivers [30, 32]. This study's focus on athletes recently completing CR limited men caregiver inclusion, likely due to the higher prevalence of CAD in male athletes and the prevalence of heterosexual couples, though systemic factors in women's diagnosis, referral, and CR adherence may also play a role [50, 61, 90]. Given that men caregivers may approach caregiving differently [34], gender-specific research on caregiving in CR is needed.

Our study focused on informal caregivers, but examining both patients and caregivers together should be the next step. Prior studies have described athletes' cardiac rehabilitation process [78, 109, 114], but hardly addressed the athlete-caregiver dyad. Our findings highlight family members' anxiety around exercise, suggesting that including caregivers could ease this concern and support rehabilitation outcomes. Our recommendations resulted from the interaction with six co-participation features. In the future, Value Sensitive Design [44] should be employed to identify core dyadic values in C(T)R, expanding co-participation possibilities. We acknowledge that our recommendations do not exhaustively address all design possibilities for managing care tensions and encourage further exploration of alternative negotiation tools. Further research is needed to (1) identify these tensions in specific health contexts and (2) address them in co-participation design.

The patient-caregiver relationship itself is crucial [53]. Imbalanced or strained dynamics can be aggravated by technology. Our conclusions are drawn from dyads with lower co-dependence, where research is limited. Future studies should explore how these mechanisms apply to more dependent relationships where patients require practical caregiving and investigate guidelines for dyads facing relational challenges before diagnosis.

7 Conclusion

This study offers a caregiver-centred perspective on co-participation in cardiac telerehabilitation, focusing on caregivers of recreational athletes – a group navigating unique dynamics of autonomy, identity, and recovery. We highlight how involvement is shaped by shifting relational dynamics, emotional labour, and boundary negotiation. By applying dyadic coping and illness management theories, we surface key mechanisms such as shared management and emotional support that can guide caregiver-inclusive design. Our work contributes to CSCW by reframing co-participation as a negotiated, time-bound process, and by offering design implications for systems that support emotional well-being, mutual trust, and dynamic role calibration.

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