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RESEARCH ARTICLE

Understanding Complexities in Collaborative Management of Knowledge on Advance Care Planning for Multi-morbid Patients Within Personalized Integrated Care

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Abstract

Healthcare has shifted from paternalistic model of care to patient-centered care where shared decision making is key. The need to share and manage contributions and expertise of different healthcare professionals underlines the relevance of collaborative knowledge management (CKM). However, CKM in healthcare requires one to understand the complexities in integrating multiple aspects of care and the challenges associated with interdisciplinary collaboration and knowledge sharing among healthcare providers. In this study, we use a system modeling approach to understand the complexities in collaborative management of knowledge on advance care planning for multi-morbid patients, within personalized integrated care. To achieve this, focus group discussions (FGD) with 11 participants from Basque Public Health System (Osakidetza) in Spain were involved in identifying the key challenges and developing a systemic thinking model. As a result, three key challenges were identified, i.e., (1) culture, where citizens are not willing to talk about death; (2) healthcare professionals, whose attitude and perspectives need to change; and (3) the current system, that has to change its care model towards a holistic and a shared care model. From the developed causal loop diagrams (CLDs), it is noted that perpetuation of fragmented and paternalistic care is likely to get worse without recognition of the advance care plan (ACP) as a social need and as a crucial part of the clinical practice change.

Keywords System modeling · System thinking · Collaborative knowledge management and advance care plan

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1 Introduction

The information age and varying patient needs are driving a shift in the healthcare landscape. At the same time, chronic diseases, social determinants, and resource limitations continue to add pressure. Healthcare has thus shifted from paternalistic mode of care where healthcare professionals are in control to patient-centered care (PCC) [1]. With PCC, focus is on individual needs, i.e., patients are identified as persons who live in various settings that are supported by a social context that listens, informs, respects, and allows their wishes to be honored during their health care journey [1, 2]. The patient-centered perspective requires that a carer holistically take into account what is known about the patient and recognize the patient as a unique human being before forming a diagnosis of the patient's illness. This indicates an increasing need for multifaceted decision-making.

Multi-morbid patients often have complex medical conditions that require comprehensive coordinated efforts from various healthcare specialties [3–7]. They also have to deal with multiple care service providers which make decisions on healthcare preferences, curative or palliative treatment, and end-of-life difficult [8–10]. One of the ways these challenges are being addressed is through personalized integrated care (PIC). PIC is an evolving field where diagnosis, management, and treatment of each patient are tailored to their individual needs and characteristics [11]. PIC is characterized by therapeutic relationships, shared power and responsibility among health professionals and patients, person and citizen empowerment, and trust and communication with the patients [1]. PIC supports tracking of disease development, early interventions, and disease management and thus has become more central to patients with chronic conditions [12, 13]. To aid the PIC process, a comprehensive basis for individually tailored personalized care plan is vital (Fig. 1).[1]

A care plan is a consultative process that supports patients' decision making about the future of their healthcare up to end-of-life [8–10]. The consultations are made with health care providers, family members, and important others [14]. Throughout this process, patients are informed and empowered allowing them to individually share documents, make comments, and engage in the decision-making process. As patients advance in age, their health condition deteriorates and illnesses become more severe. At this point, the advance care plan (ACP) is implemented (see Fig. 2). An ACP is a document that formalizes the patient's decisions (preferences) on medical care. The advance care planning process supports adult patients at any age or stage of health to understand and share their personal values, life goals, and preferences regarding future medical care [9, 10, 15]. Care planning is therefore central to integrated care. It aims to deliver more personalized and targeted care. Yet, integrated care seeks to improve the quality of care for individual

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[1] Here, we use personalized integrated care though we note the interchangeable use of this term with personalized care and personalized/precision medicine in some studies. For clarity, the distinction in these terminologies is illustrated in Fig. 1.

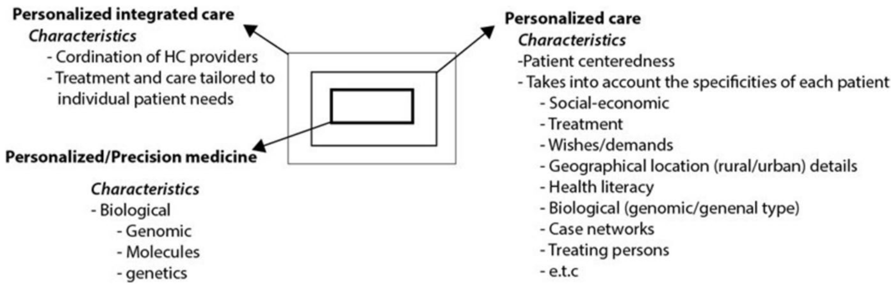

Fig. 1 Difference between personalized integrated care, personalized care, and precision medicine

patients, service users, and care providers by ensuring that services are well coordinated to meet their needs.[2]

Managing and coordinating care for multi-morbid patients especially those on ACP is challenging. This is due to multiple coexisting health conditions, medication regimens, treatment protocols, and potential interactions between different diseases and medications [16]. Meeting the various patient needs therefore requires multiple healthcare knowledge experts to collaborate and work together towards sustainable and successful patient care and treatment [4, 5, 17]. These collaborations establish a complex web of cause-and-effect relationships. Understanding these relationships helps in creating more effective and compassionate care strategies.

Contextualizing patients' information requires transforming the roles of healthcare professionals from paternalistic (authority) to ones with goals of partnership, empathy, and collaboration [2]. van Dongen et al. note that health care professionals often develop individualized discipline-specific care plans. But the increasing complexity of care for multi-morbid patients requires synchronization of these individualized discipline-specific care plans into a shared care plan [18]. A shared care plan is a collaborative and shared document established through joint interprofessional collaborations among professionals [18, 19]. Creating a shared care plan that maps care processes and distinctly articulate the role of each provider and patient in the care process is essential [19, 20]. Patients' utilization of a shared care plan and the diversity and contradicting needs associated with multi-morbid patients create new learnings [16, 20–23]. Capturing and sharing these learnings from patient illness progressions through integrated healthcare activities is a critical enabler to supporting a connected approach for healthcare design and delivery. In order to realize a comprehensive and well-coordinated treatment and care plan, collaboration is important. This allows a range of healthcare professionals to collaborate on shared goals in a unified and integrated manner [24].

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[2] Note that care planning aims to deliver more personalized and targeted care yet, integrated care seeks to improve the quality of care for individual patients, service users and care providers by ensuring that services are well coordinated to meet their needs.

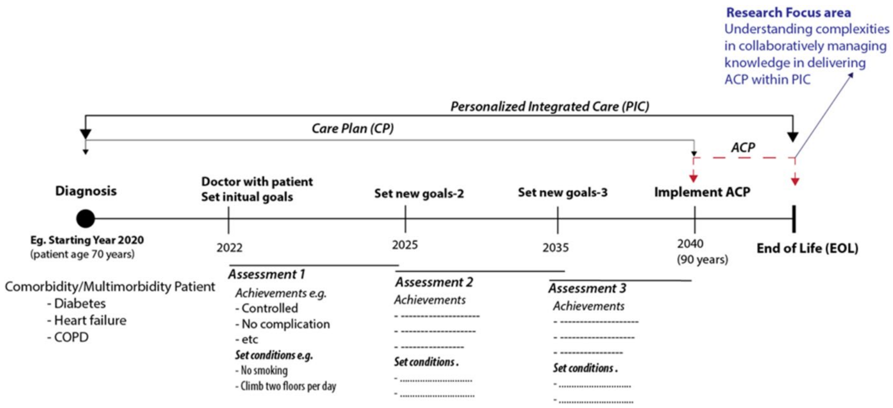


Fig. 2 Stages of a patient's care plan assessments, ACP implementation stage, and research focus

In this study, we use the term collaboration in the context of a group of people with differing perceptions and aspects of a problem actively working together to achieve specific goals. This group of people collectively define goals, share responsibilities, have shared authority, and are accountable to the results [25, 26]. Effective collaboration requires a high level of cognitive participants' involvement, as well as preparedness to contribute to the creation of a shared understanding [27]. Collaboration in clinical decision making (CCDM) is contextual, process-driven with mutual participation and cooperation among multiple stakeholders, and is supported with information communication technologies [28, 29]. It includes examining, synthesizing, interpreting, and evaluating information to produce evidence-based choices of action in a clinical set-up [29]. Successful CCDM depend on varying factors among which is (healthcare professionals' clinical "mindlines," (b existing knowledge structures, (c disease pattern recognition, (d inherited culture, (e role perception, etc. [30–32].

The involvement of various healthcare professionals and the complexities in personalized integrated care demonstrate a need for collaborative knowledge management (CKM). CKM is perceived as an important economic resource to personalized integrated care because (1) it provides insights in understanding how to improve healthcare practices, healthcare process, and outcomes; (2) encourages resolving problem(s) collectively in an effective and efficient manner; and (3) allows patients to individually share documents, make comments, and engage in discussions [33]. To successfully implement CKM in healthcare, one needs to understand the complexities in integrating multiple aspects of care,and the challenges associated with interdisciplinary collaboration and knowledge sharing among healthcare providers.

1.1 Context of the Basque Health System

The Basque Country is one of the 17 autonomous regions with approximately 2.18 million inhabitants located in the north of Spain. It is a representative scenario of Organization for Economic Co-operation and Development (OECD) countries that are rapidly aging and with death rates related to frailty correspondingly growing. Among the population, only 1.47% had their advance directives registered, as a proxy of ACP engagement, although 22% of the Basque population are over 65 years old today, with a high prevalence of chronic diseases and an increase in people's frailty and dependency. Each autonomous region in Spain has its own public health system, ruled by same state laws but different regional norms [34]. The population from OECD countries is aging, and ACP awareness has risen on the people-centered health policies. In most countries, deaths within hospitals decreased between 2009 and 2019 which possibly emphasizes the initial efforts to meet and align with people's preferences. There is still a long way to go to face the incipient demand as the number of people dying of diseases that would benefit from ACP is forecasted to increase from 6.3 million in 2017 to 9.7 million in 2050.

The Spanish and Basque societies emphasize familial support and access to universal healthcare, prioritizing quality of life despite health challenges. Both cultures highlight the importance of support networks and adaptability in managing chronic illness within their unique cultural frameworks [35]. Regarding death, the cultural context of Spanish and Basque societies is deeply intertwined with their historical, religious, and communal traditions. Catholicism plays a significant role in emphasizing the afterlife beliefs that have shaped elaborate rituals such as the Day of the Dead and All Saints' Day. Family ties are paramount, and public displays of grief are accepted in some regions, reflecting a communal approach to mourning [36]. The Basque Country cultural resilience and strong sense of identity also influence its relationship with death with rich mythological narratives, a deep connection to nature, and a focus on preserving heritage [37].

Note that the application of system thinking to health challenges is not new. Previous studies have applied system thinking in diverse cultural and healthcare settings beyond the Basque region, i.e., to gain insight into the complexity of obesity-related behaviors among youth [38], to assess sustainability challenges in healthcare systems [39], to address complex public health and health services problems [40], and there also exists systematic reviews of the application of systems thinking to the field of health and public health [41–43]. Systems thinking models are noted to provide new opportunities to understand and continuously test and revise understanding of the nature of things [44].

This study is therefore aimed at understanding the contributing factors, the cause-and-effect relationships, and the complexities in collaborative management of knowledge on advance care planning (ACP) for multi-morbid patients, within personalized integrated care. The rest of the paper is organized as follows. In Sect. 2, we present materials and methods. In Sect. 3, we present the results indicating the model development process. In Sect. 4, we discuss the resulting causal-loop diagram (CLD). In Sect. 5, we draw conclusions.

2 Materials and Methods

In this study, we use a system modeling approach. This approach includes both "soft" techniques and "hard" techniques [45]. Here, we use the soft technique because it allows tackling of complex and unstructured problems with multiple stakeholders [45]. In [45, 46], it is noted that applying system modeling in healthcare improves outcomes through evidence-informed analysis by capturing structures and interactions of feedback loops, hence allowing stakeholders to understand how changes manifest. One of the system modeling approaches is system thinking [47]. The term systems thinking was coined by Barry Richmond in 1987 and is defined as "a set of synergistic analytic skills used to improve the capability of identifying and understanding systems, predicting their behaviors, and devising modifications to them in order to produce desired effects" [47]. Systems thinking supports understanding of the cause-and-effect relationships between or among variables and analysis of the dynamic interactions between variables overtime [45, 48]. Cause-and-effect relationships occur in a wide range of contexts, i.e., physics, engineering, social sciences, economics, and environment [49]. They describe the connection between events or actions, where one event (the cause) leads to another event (the effect) [50]. Identifying these relationships helps in understanding the underlying mechanisms of a process, predicting outcomes, and making informed decisions [49]. In cause-and-effect relationships, correlation does not always indicate causation. It is therefore important to consider the evidence and analyze the context to determine if there is a true cause-and-effect relationship [49].

The system thinking approach uses causal-loop diagrams (CLDs) to capture structures and interactions of feedback loops, to model the causality, and to brainstorm on a given problem [48, 51]. The causal relationship in CLD indicates one element affecting another element. Representing the feedback of related elements requires including a positive (+) and negative (−) polarity to the CLD diagram. A relationship is *positive* if the condition in which a casual element, (A), results in a positive influence on a casual element on (B) (A –-> +B), i.e., an increase of "A" value responds to the "B" value with a positive increase. A relationship is *negative* if the condition in which a causal element, (A), results in a negative influence on (B) (A –->-B), i.e., an increase of "A" value responds to the "B" value with a decrease [48, 52]. A closed sequence of causes and effects (closed path of action and information) leads to a feedback loop (reinforcing (R) and balancing (B)). For more explanation, see appendix A and ref. [53].

2.1 Stakeholder Involvement in Model Development

Integrated care in the Basque region is structured in thirteen (13) different organizations, including both primary care and hospital services. Each of these integrated care organizations covers a population of 150,000 to 400,000 inhabitants. Out of the 13 healthcare organizations, a representative group of four (4) were selected for participant recruitment based on their specialized focus on advance care plans for chronic patients, logistical time constraints, and the ease of accessing established contacts. Note that in the focus group discussions, patients were not included due to the kind of information required and the kind of diseased patients involved in the study.

2.1.1 Stakeholder Identification and Categorization

A focus group as defined by Stewart and Shamdasani [54] is a moderated discussion among six to twelve persons discussing a topic under the direction of a moderator whose role is to promote interaction and keep the discussion on the topic of interest. The aim of conducting the FGDs was to (1) obtain data from a synergized group of healthcare professionals' interaction on challenging factors in collaborative management of knowledge on ACP for multi-morbid patients within personalized integrated care, (2) allow researchers gain a deeper understanding of the complexities involved, and (3) build a CLD model.

Stakeholder identification was iterative that required clear understanding of the problem (Reed, et al., 2009). To avoid ad hoc stakeholder identification, a preparation meeting was held comprising of a team of eight (8) persons. Each person on the team had a clear understanding of the problem. An initial meeting was held, chaired by the key researcher with all persons present. As a result, the following were obtained: (a) a proposed list of participants, (b) two persons who were tasked to identify participants that were to take part in the focus group discussion (FGD), and (c) categorization/grouping of the proposed participants according to their role in the healthcare system, expertise of the research area and availability. This identification process is in line with Mitchell et al. [55] and Reed et al. [56] who in their articles provide procedural steps for stakeholder analysis.

In the second preparation meeting, a list of the identified participants was presented and it was agreed that focus group participants be divided into two groups (group A and group B). Group (A) comprised of healthcare professionals and group (B) comprised of decision-makers and healthcare managers. This was because the stakeholders' responsibilities for each group differ [57]. Healthcare professionals are more in implementation/realization, while healthcare managers and decision makers' interests are in operationalization of ACP. After the meeting, the selected participants were contacted through email and phone calls. Due to their busy schedule, not all participants agreed to take part in the study. Those that accepted were requested to suggest their available dates, and based on their feedback, a final date was selected. In total, three preparation meetings were held prior at Kronikgune Institute for Health Services Research (currently referred to as Biosistemak Institute for Health Systems Research). The aim of these meetings was to deliberate and agree on a number of activities: (1) the focus discussion agenda and dates, (2) moderator roles, (3) focus group session setting, and (4) the required working materials. A week to the FGD, an agenda (see appendix B), and working documents were emailed to all participants.

Table 1 FGD guiding questions

Guiding question: "What challenges do you face in collaboratively managing knowledge for patients with multi-morbid conditions on Advance Care Plan?"

No	Guiding steps
1	The moderator affixes the problem variable in the middle of the sheet
2	Request participants to specify the challenges as the moderator puts/records them on a colored post-it note, placing them one below the other, so that everyone can see them clearly
3	Request participants to identify the cause(s) for each stated challenge
4	Request participants to identify the consequences for each stated challenge (Note: it may be that what was initially identified as a challenge becomes a cause or a consequence as participants discuss)
5	Observe if there are imbalances between the challenges and, if so, confirm with the group
6	Try to achieve consensus among participants on the final model (in both the first and second FGD sessions), prioritize a maximum of three challenges

2.1.2 Conducting the Focus Groups

For this study, three FGDs were conducted. Two FGDs were conducted in parallel with two distinct stakeholder groups. The third FGD was a combination of both groups. During the combined FGD, participants were tasked to make presentations of their results from the previous session in order to identify commonalities and unify a set(s) of variables. To facilitate the FGDs, two moderators were assisted by two co-moderators (rapporteurs). The two moderators had experience in conducting FGDs and were more aware of the research problem. One of their roles was to ensure that all the given steps stated in Table 1 were followed. They also took notes keeping as much eye contact as possible with the participants, thus making it easier for everyone to contribute. The co-moderators on the other hand were responsible for taking notes (which would later complement the recordings), recording, monitoring time, and looking at non-verbal communication. The co-moderators were allowed to intervene when appropriate.

The identified challenges were pinned on the board. For each challenge, participants were asked to identify the cause and consequence then direct and indirect causes and consequences (see Fig. 3).

On completing the FGDs, two researchers examined and categorized the data collected from healthcare professionals, and the other two examined and categorized data from healthcare managers. Data were presented in a scheme of three blocks. The challenges identified by participants were placed in the center, the causes on the left, and the consequences on the right. While reporting, we chose to stay closer to the original meanings and contexts, summarizing and presenting data using the participants′ words [58].

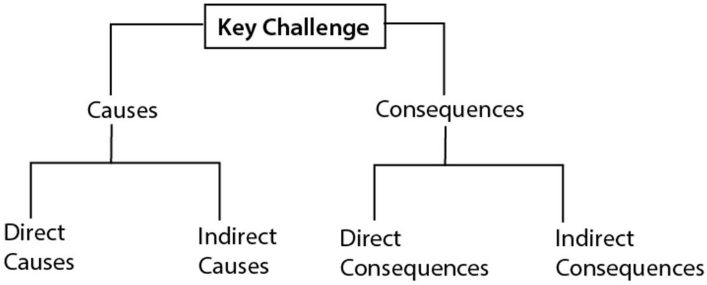


Fig. 3 An illustrative example of the guiding steps

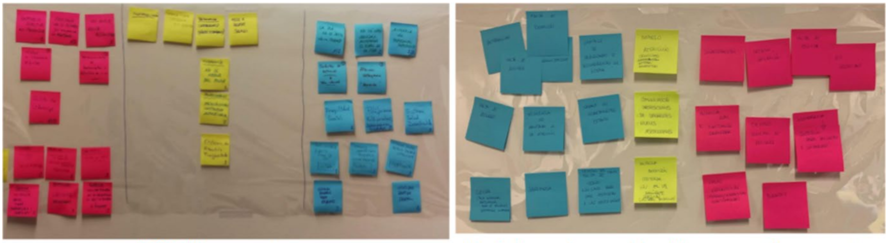
3 Results

The materials used during the FGDs included post-it notes (sticky notes), recorders, cellophane paper to place the post-it notes, and markers and tape. The cellophane papers were used to stick post-it notes as participants identified the different variables. This helped to keep the walls clean. In the subsection below, we present results from the FGDs.

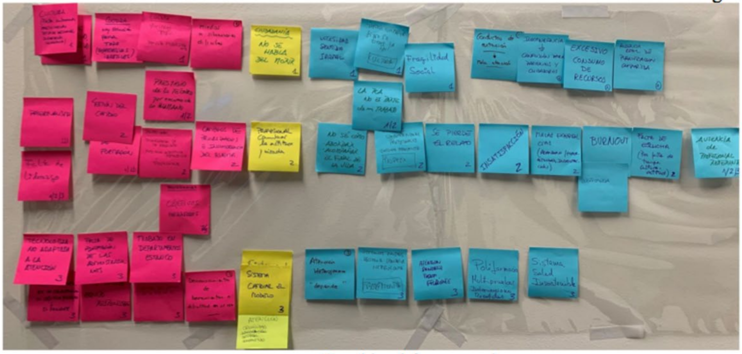
3.1 Identified Key Challenges in Collaborative Management of Knowledge on ACP for Multi-morbid Patients Within Personalized Integrated Care

Three key challenges were identified: (1) *culture*—where citizens do not talk about death; (2) *healthcare professionals*—change of attitude and perspective, i.e., willingness, commitment, and self-efficacy; and (3) *the system*—changing the care model towards a holistic and shared care model. For culture, one of the participants argued that "We have to change the culture of talking little about illness and about dying. The important thing is that the disease catches us thinking, that there is a cultural change. It is also important for the public to be able or willing to talk about the disease about dying." Another participant stated that "we are in a society that believes in survival and immortality and personalized medicine and so on., and it doesn't think that we are finite and we are going to die, we don't see dogmas and that's it." Thus, the citizens/community are influenced, not only thinking that everything has a solution but also that the media generate a culture and influence on people.

The second identified key challenge was the healthcare professional (HCP) change of attitude and perspective. This challenge is attributed to a number of factors: the HCP's attitude and perspectives towards ACP and patient-centered care, self-efficacy ("Am I competent to develop planning with patients?"), readiness and engagement of practitioners/professionals, the complex chronic patients polypharmacy management, the lack of social support, the lack of a clear guide/communication and ethics on how to work with palliative patients, and the limited time HCPs have to learn how to do things. It was noted that "professionals do not dedicate time that the person needs, and this is often related to involvement, predisposition, training, culture as a chain and not knowing how to approach the subject well."



HCPs focus session Decision makers and health manager focus session



Combined focus session

Fig. 4 Outcomes for both sessions of the focus group activities

The third identified key challenge was an institutional/system challenge—*changing the care model towards a holistic and shared care model*. Participants noted that there is need for institutional support in planning the protocol so that the care model is prioritized and not taken as a voluntarism of professionals. Participants argued that by protocolizing the care model, professionals are made to commit themselves. That way they are made to feel that they have the support needed to develop and implement the model. Other contributing attributes to "changing to a shared care model" include fragmented care (lack of coordination between levels of care), clashing care objectives (comfort vs. survival of people), a need for coordination and communication between primary care and hospital care, and a lack of time (sometimes there are many patients to treat in a short time).

After identifying the three key challenges, participants were further tasked to identify the causes and consequences to the specified key challenges (see Fig. 4 and Table 2). For each identified key challenge, causes and consequences were defined.

3.2 Feedback on the Identified Key Challenges, Their Causes and Consequences

Culture-citizens do not talk about death: it was noted that the society believes in survival, immortality, and personalized medicine. Therefore, it does not think that "we" are finite and are going to die. Walking towards a cultural change that promotes talking about death requires willingness and predisposition of the public to talk about death. It was further noted that "healthcare professionals have to change the culture

Table 2 Identified key variables, their causes and consequences

Key challenge 1: culture (we do not talk about death)				
Causes			Consequences	
Fears of difficult situations			Avoidance behaviors that lead to bad quality care	
Reactive approach, not preventive			Incoherent care directions that cause confusion to patients and informal carers	
Culture: – Taboo society and Mediterranean family – There is a solution for everything (creating unrealistic expectations) – Lack of autonomy, participation, decision-making, citizenship information			Excessive use of resources	
			Real lack of shared planning	
			Social fragility	
			Unrealistic perceived need	
			Difficulty to share without the information	
Key challenge 2: (HCPs' change of attitude and perspective towards a shared care model)				
Causes			Consequences	
Lack of leadership	Lack of training	Prestige of the technical over the human	The advance care planning (ACP) is not part of my job	Lack of reference professionals
		Change management	Lack of listening (due to time, culture, attitude)	
		-Technification of medicine,	Being under pressure and emotionally overwhelmed	
		-Paternalistic academic training and fragmented	Different professional behaviors Paternalist approach	
		Change in priorities and inconsistencies of the system	Loss of the patient narrative/story	
		Paternalism	I do not know how to address, accompany, the end-of-life	
Key challenge 3: system (changing the care model)				
Causes			Consequences	
Lack of knowledge of tools/difficulty on using them			Less efficient healthcare	
There is no responsible team			Different messages, heterogeneous health care, fragmented health care	
Lack of adaptation of administrations			Polypharmacy, multiple tests, repeated interventions	
Technology not adapted to care model			Heterogeneous care	
Fragmentation: culture of "this is not mine" -work in sealed departments -lack of firmness in the orientation towards the main target, the patient -shared vision of care			Unsustainable healthcare system	

of talking less about survival and more about the disease, about dying.” The important thing is to bring about a cultural change.

Several causes were identified as affecting variable “We don’t talk about death.” These include (a) *social culture of survival*: there is a widespread culture in the population that there is a need to look for tools to survive and that there is always a solution for everything; thus, unrealistic expectations are spread among people. It is therefore a “taboo in the society” to talk about the end-of-life or death. People are not comfortable thinking and talking about death; (b) *the cultural importance given to the family in the society*: for a Mediterranean family, everything is shared with the family so HCPs address the family directly without even asking the patient who you want to inform; (c) *lack of patients’ autonomy and participation*: there is no training or participation in decision-making and the patients’ perspective of their environment is lacking in this process; (d) *fears of difficult situations*: in general, both the population and in many cases the HCPs are afraid to face situations that they do not know how to deal with; therefore, training is necessary and a reactive approach from HCPs, not preventive.

The identified consequences for variable *culture-citizens do not talk about death* include (a) avoidance behaviors that lead to bad quality of care (not wanting to talk about death) and (b) a more fragile society with a poorer level of health is more dependent on the system. Also, the lack of information culture to normalize thinking about death leads to a fragile society. The culture of survival creates false expectations to the patients especially when the HCPs do not communicate/inform the patient. As a result, there is an unsustainable and totally ineffective health system. To avoid this, the HCPs need to talk and communicate to the patients “that their quality of life is going to be worse, and that the scanner is not going to be of any use, for example.” *This however takes time and some of the patients will not understand it*; (c) unrealistic perceived need: the society is hindering a more rational end-of-life option because its objective is survival. “HCPs could convey that there are limits and other ways, but there is no such support from majority of the healthcare professionals”; (d) peoples’ difficulty to share about their situation: the population does not feel comfortable sharing their situation and the HCPs do not know how to face conversations about the end-of-life with the patients; (e) actual absence of shared planning of care adapted to the individual, i.e., shared care planning is believed to be a wish and not a reality; (f) there exist thousands of contradictory information and the inconsistency of messages between levels of care generates confusion within patients and caregivers. Thus, professionals are unable to plan well for care; and (g) excessive use of resources for care activity (e.g., tests and consultations).

The CLD model presented in Fig. 5 depicts the participants’ views of the causes and consequences for *culture (We don’t talk about death) challenge*. The variables presented in this sub-model are based on the outcome of Table 2 with alterations/revisions of variables to give a more meaningful representation of the causal influences (see Table 3).

Healthcare professionals—change of attitude and perspective towards a shared care model: a number of influencing factors were identified as depicted in Fig. 6. It was noted that HCPs’ primarily provide rapid response to destabilizations; thus, “the emergency route is always used and work has been done to have direct access to the hospital. But it

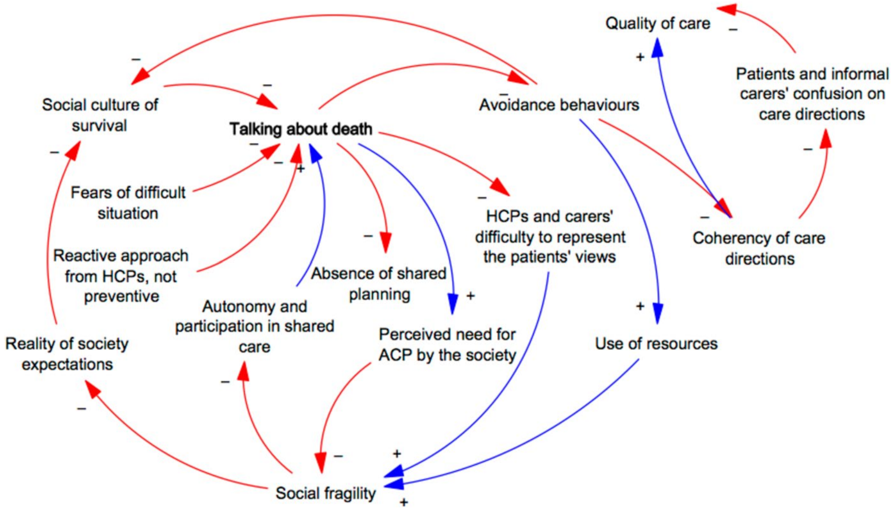


Fig. 5 A causal model for talking about death

Table 3 Examples of modified variable names

	Initial stakeholder variable	Modified variable
1	We do not talk about death	Talking about death
2	Culture	Social culture of survival
3	Reactive approach, not preventive	Reactive approach from HCPs not preventive
4	Creating unrealistic expectations	Reality of society expectations
5	Lack of autonomy, participation, decision-making, citizenship information	Autonomy and participation in shared care
6	Real lack of shared planning	Absence of shared planning
7	Unrealistic perceived need	Perceived need for ACP by the society
8	Difficulty to share without the information	HCP and cares' difficulty to represent patients' views
9	Excessive use of resources	Use of resources
10	Bad quality care	Quality of care
11	Incoherent care directions	Coherency of care directions
12	Confusion of patients and informal carers	Patients and informal carers' confusion on care directions

Two variables (*general belief "there's a solution for everything"* and *taboo society and Mediterranean family*) were deleted from the initial model because they were implied in variable "social culture of survival"

has not worked. We have routes such as the pluripathology route that is implemented, but it is not perfect"; secondly, polypharmacy management is complex for chronic patients because these types of patients contact different specialists and thus drug interactions arise. The lack of a supervisor to review and adjust the patient's medication also affects successful implementation of ACP. Furthermore, HCPs' self-efficacy: one of the stakeholder's asked "Are HCPs competent to develop a planning with patients?" This includes

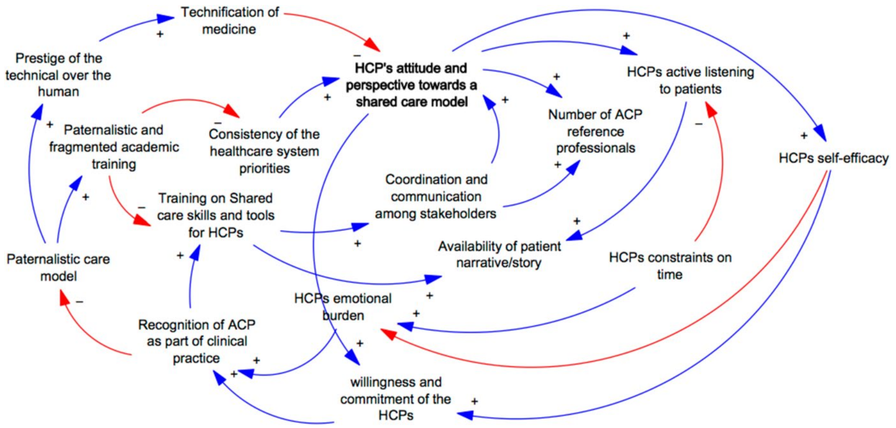


Fig. 6 A causal model for HCPs' change of attitude and perspective towards a shared care model

their readiness, willingness, and commitment. It was observed that in general, "HCPs do not dedicate the time the person needs, and this is often related to involvement, predisposition, training, culture as a chain and not knowing how to approach the subject well" which affects ACP implementation. Overall, HCPs expressed that they have little time to learn how to do things (time constraints); thus, lack adequate and quality time to provide suitable response in relation to the paternalistic care model.

A number of causes were identified for variable "HCPs' change of attitude and perspective towards a shared care model," and these include (a) changes in priorities and inconsistencies in the system: this influences the objectives of the work and does not allow for continuity thus, conflicting care objectives (comfort vs. survival of people). It was argued that care objectives conflict because they are not aligned between levels. What causes this is unknown, it may be multifactorial, e.g., professional training, professional culture social culture etc. Stakeholders expounded that social culture is where there is no room on the part of many professionals. To stop polypharmacy and selling the image that we must always do something until the end-of-life generates more problems; (b) fragmented objectives: there are no clear objectives that are passed onto the HCPs. So often, the objectives change according to the new needs, challenges, or problems that appear in the health system, and at the community level; (c) prestige of the technical over the human (technification of medicine): professionals tend to order tests on patients instead of taking the time to analyze the situation or talk to the patient and seek the tools available in the system to help address the patient's health problem; (d) paternalism: the paternalistic model of sapience is a barrier, "HCP's who consider knowledge to be theirs, tend to set a plan for the patient without considering the patient's needs. It is necessary to change and listen to the needs of patients and make this a working tool, seeking a balance between autonomy and support in decision making, neither professionals nor patients are used to this." Shared planning in patient profile is laborious and HCP fear to face issues especially when they lack the required training.

The identified consequences for variable “HCPs’ change of attitude and perspective towards a shared care model” include (a) distance between primary and hospital: there is no communication and coordination of activities carried out by HCPs (fragmented care); (b) persistence of the paternalistic approach; (c) lack of recognition of ACP as part of clinical practice: the HCPs feel that the ACP is not part of their job, due to lack of training and support by the organization. Lack of predisposition and knowledge of HCPs and sometimes the lack of time (which is a reality) are used as an excuse by HCPs; (d) different behaviors of HCPs (how to approach ACP): there is a need to develop training and sharing programs among HCPs; (e) HCPs feel pressured (no time for anything anymore) and emotionally overwhelmed; there is dissatisfaction, discontent, and weariness; (f) lack of listening to the patient (due to time, culture, attitude); (f) loss of the patient narrative/story: “the patient is no longer spoken to or about. It is impossible to focus attention on the patient if the patient’s narrative is not available”; (g) bad experiences: in the type of care (hyperactivity of the clinic, biased care; lack of comprehensive care, of active listening to the patient) and in the emotions generated (suffering, abandonment, dissatisfaction, burnout of the professionals).

Based on the stated variables, a sub-model (Fig. 6) was derived. Note that some variable names were revised. For example: “change in priorities and inconsistencies of the system” was revised to “consistency of healthcare system priorities” and “lack of ACP and EHR training” was revised to “Training on shared care skills and tools for HCPs.” Variables like “change management” and “different professional behavior paternalistic approach” were deleted because they were already implied within other variables or they were not well elaborated in the description text. Thus, hard to identify their causality.

The system—changing the care model towards a holistic and shared care model: a number of influencing variables were identified: (1) lack of institutional advocacy to support, protocolize, and encourage shared care planning; (2) confronting care objectives; (3) fragmented care with conflicting objectives, i.e., there is a lack of coordination between levels of care due to internal communication barriers between administrations. This makes collaboration very difficult due to security problems like access and confidentiality; (4) limited time on the side of the HCPs due to the high number of patients to see and treat in a short time; (5) absence of a referent professional in primary care to coordinate care and make decisions; and (6) difficulties in accessing social services. This may require a change to a more comprehensive model that includes socio-health area.

When asked to identify the causes for variable “changing the care model towards a holistic and shared care model,” participants argued that the current care model is not in line with society needs. That is why there is little willingness to change. Secondly, the technology is not adapted to care. The developers who are technical personnel are not on the teams that discuss what is needed from these technologies (teams are mostly made up of HCPs). In addition, patients are also unable to adapt to the technologies because they either lack knowledge of tools or face difficulty in using them. Participants stated that "there are so many tools available to practitioners, that many times practitioners do not know that there is already a tool available for ACP, and in many occasions the HCPs do not know how to use the tools available in history." Also, there is no responsible team to coordinate and follow up ACP activities. Further, most people work in sealed departments and "everyone writes their own story, it is not really shared, not even with the HCPs involved in a person's care." This results in a lack of shared vision of care or teamwork. Finally, there are two extremes of HCPs, the one who says "this does not concern me at all" and the one who says "the patient is mine." This leads to limited or no focus on patient needs and a lack of firmness in the orientation towards the patient.

The identified consequences include (1) unsustainable healthcare system and (2) multiple tests/polypharmacy. It was stated that it is easier to ask for a test or to give more treatments than to talk about death; (3) heterogeneous care (this depends on the attitude and/or commitment of the HCP); (4) lack of listening "a patient is either not there or not listened to. Everything for the patient but without the patient," and (5) times are not adapted to the needs of the patient and the HCPs, and full schedules make it difficult to accommodate new needs. It was noted that there is an overload of tasks and appointments, and if the professional cannot manage them, s/he cannot make changes in the way s/he works thus, it is very difficult to adapt to the needs, and there is less efficient healthcare. In Fig. 7, we represent the identified causes and consequences to change towards a holistic and shared care model.

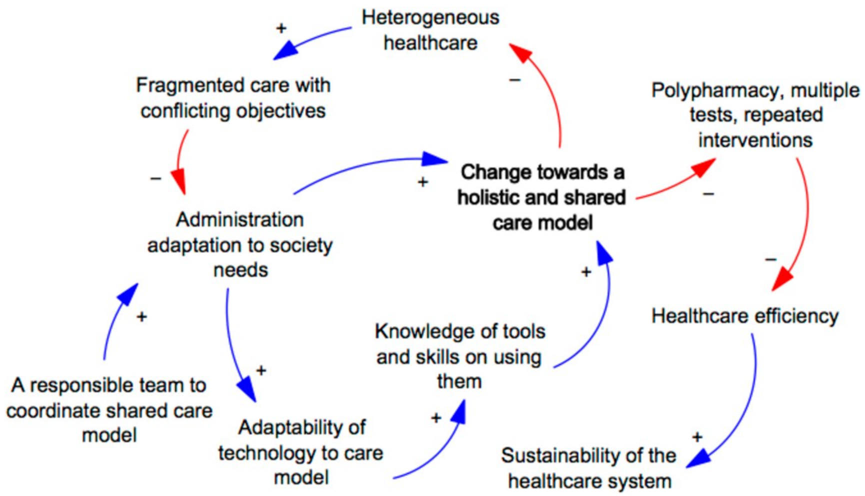


Fig. 7 A causal model for change towards a holistic and shared care model

4 Discussion

To understand the contributing factors, the cause-and-effect relationships, and the complexities in collaborative management of knowledge on advance care planning (ACP) for multi-morbid patients within personalized integrated care, a system thinking approach was applied with a focus on the mental models of stakeholders. Stakeholders were involved in constructing the system thinking model to give a holistic perspective on the possible solutions as countermeasures of the problem [59]. Success of this approach depended on clearly defining the problem and precisely formulating the question to be addressed. The importance was to collectively construct a social learning process as explained by Etienne et al. [60] that results in building a shared and collective mental model of the problem at hand [60–62]. In order to produce the desired effect of improving the quality of healthcare, the systems thinking approach allowed us to use a set of synergistic analytic skills to improve the capability of identifying and understanding the ACP systems. Results revealed that collaboratively managing knowledge for multi-morbid disease patients on ACP experiences multiple challenges that led to poor quality of care being rendered to patients. Among the featured challenges are talking about death, HCP's attitude, and perspective towards a shared care model, polypharmacy, multiple tests, repeated interventions, etc. which are a common phenomenon in ACP health management, etc.

To give a holistic view of the complete model, we merge the sub-models in Figs. 5, 6, and 7 into Fig. 8. In this figure, there are several loops most of which are reinforcing loops and are explained as follows.

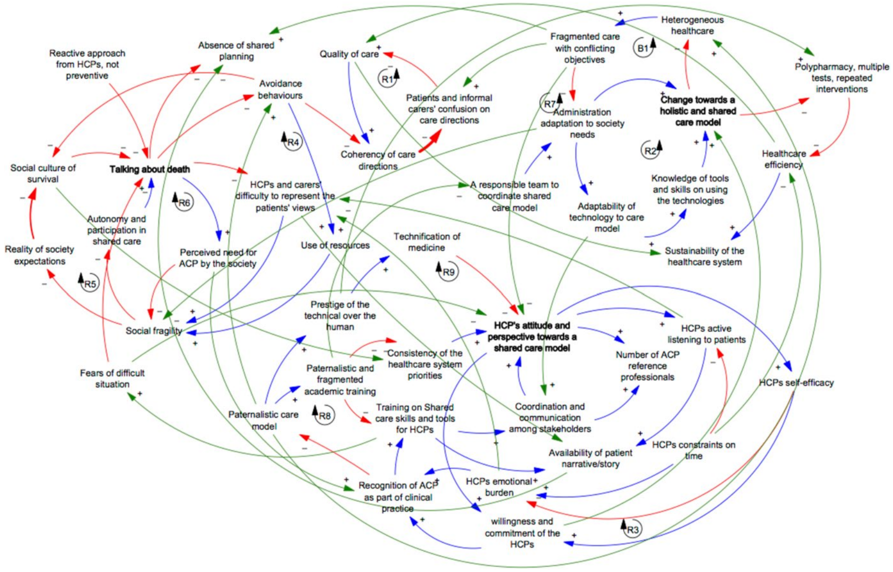


Fig. 8 A unified causal loop model for the complexities in collaborative management of knowledge on ACP for multi-morbid patients within personalized integrated care

- R1 loop consists of three factors and is explained as follows: patients' and informal carers' confusion on care directions reduces the quality of care; the quality of care on the other hand positively influences the coherency of care directions.
- R2 loop consists of six factors and is explained as follows: adaptability of technology to care model positively influences knowledge of tools and skills on using the technologies which then positively influences the change towards a holistic and shared care model. The change towards a holistic and shared care model, however, reduces heterogeneous healthcare which then positively influences fragmented care with conflicting objectives. The fragmented care with conflicting objectives then reduces administration adaptation to society needs which positively influence adaptability of technology to care model.
- R3 loop consists of six factors: HCPs self-efficacy positively influences their commitment and willingness which then positively influences recognition of ACP as part of clinical practice. Self-efficacy affects HCPs' abilities to offer effective support and the amount of support they provide because it requires individual self-assessment for a given task [63]. It is further argued that, since people are more likely to attempt tasks, they feel capable of enacting,therefore, it is reasonable to assume that self-efficacy and willingness to support are positively related. Recognition of ACP as part of clinical practice positively influences training on shared care skills and tools for HCPs which improve coordination and communication among stakeholders. When coordination and communication among stakeholders improve, HCP's attitude and perspective towards a shared care model also improve.

- R4 loop consists of five factors: social fragility reduces autonomy and participation in shared care which then positively influences talking about death. The positive influence on talking about death leads to a reduction in the avoidance behaviors which then increases use of resources.
- R5 loop consists of five factors: talking about death negatively influences HCPs' and carers' difficulty to represent the patients' views, this then increases social fragility. As social fragility increases, reality of society expectations reduces which negatively influences the social culture of survival.
- R6 loop consists of four factors: the more people talk about death, the more there is perceived need for ACP by the society, which then reduces social fragility. As social fragility reduces, autonomy and participation in shared care increase and the more people talk about death.
- R7 loop illustrates interdependence between HCP's attitude and perspective towards a shared care model, willingness, and commitment of the HCPs, change towards a holistic and shared care model, heterogeneous healthcare, and fragmented care with conflicting objectives. These interdependences are explained as follows: as the HCP's attitude and perspective towards a shared care model increases their willingness and commitment also increases which leads to an increase in the change towards a holistic and shared care model. This increase, however, leads to a decrease in heterogeneous healthcare which then leads to an increase in fragmented care with conflicting objectives, which then leads to a decrease in HCP's attitude and perspective towards a shared care model.

- In R8 loop, the paternalistic care model positively influences paternalistic and fragmented academic training which then negatively influences consistency of the healthcare system priorities. Consistency of the healthcare system priorities positively influences HCP's attitude and perspective towards a shared care model which then positively influences HCP's self-efficacy. The positive influence in HCP's self-efficacy positively influences willingness and commitment of the HCPs, which then leads to a positive influence on recognition of ACP as part of clinical practice.
- The B1 loop as the HCPs' attitude and perspective towards a shared care model increase, and HCP's self-efficacy also increases leading to a positive influence. As the HCP's self-efficacy increases, the emotional burden reduces leading to a negative influence. The less the emotional burden, the more recognition to ACP as part of clinical practice leading to a positive influence which also leads to a positive influence to training on shared care skills and tools for HCPs. As training on shared care skills and tools for HCPs increases, coordination and communication among stakeholders also increase, leading to a positive influence which then positively influences HCPs' attitude and perspective towards a shared care mode. Relations develop overtime as people participate, communicate, and develop the capacity for autonomy and decision-making [64].
- For R9 loop, paternalistic care model positively influences prestige of the technical over the human which leads to positive influence on technification of medicine. As technification of medicine increases, HCPs' attitude and perspective towards a shared care model also increases, leading to a positive influence. As HCPs' attitude and perspective towards a shared care model increases their self-efficacy also increases leading to a positive influence which also leads to an increase in their willingness and commitment. As willingness and commitment of the HCPs increases, recognition of ACP as part of clinical practice also increases, which leads to a negative influence to paternalistic care model. The relationship between self-efficacy, willingness, and commitment of the HCPs is supported by Cheng and Chang [65] where they argue that willingness to cooperate of individuals has a positive effect on knowledge collaboration, and Tran et al. [66] further emphasize that self-efficacy is positively related to a willingness to cooperate.
- For R10 loop, fragmented care with conflicting objectives negatively influences administration adaptation to society needs which then positively influence change towards a holistic and shared care model. The increase in change towards a holistic and shared care model decreases heterogeneous healthcare leading to a negative influence. As heterogeneous healthcare increases, fragmented care with conflicting objectives increases leading to a positive influence.

One of the insights identified from the CLD is that the social culture of survival provides mechanisms for raising awareness of patients' preferences. For example, the absence of conversations about death has been identified as influencing the representations of the patients' views and therefore feeding the narrative of that patient accurately. However, the same causal linkages suggest that an approach that ensures the HCP training on shared care skills will not fear the difficult situation of talking about death and therefore will have a clear understanding of the patient's views that can be imprinted on the narrative in a reinforcing spiral [67]. But, Hook [64] and Ocloo et al. [68] note that the mechanism(s) for effectively educating and transforming healthcare providers with the desire and skills to foster shared knowledge, shared power, patient autonomy, and shared decision-making is not known.

5 Conclusion

This study sought to identify determinants of advance care planning engagement in the context of multi-morbid disease patients within personalized integrated care and how the actors involved in the care may interact and affect the creation and implementation of the ACP. A system modeling approach was undertaken from which the causal loop diagrams were developed. This enabled the identification of the key challenges, causes, and consequences for collaboratively managing knowledge for multi-morbid disease patients on ACP. This, therefore, provided a high-level concept showing how intercorrelations and detailed cause-effect relations between variables influence those concepts at a lower level. Key insights from this causal loop diagram suggest HCPs who are convinced supporters of the shared care model will drive changes both in the healthcare systems they work for and the society their patients belong to. Healthcare professionals, in turn, have to overcome the same challenge related to talking about death. The analysis suggested that the perpetuation of fragmented and paternalistic care is likely to get worse without a recognition of the ACP as a social need and a crucial part of the clinical practice part change.

The causal loop diagram and system insights generated in this study inform discussions between patient associations, healthcare professionals, and health systems on ACP attitude and promote actions that will support positive health outcomes. The current study is an input which presents one conceptualization of the system. There are limitations as the group modeling work was restricted to a particular region and did not involve patients. Heterogeneity within the group was ensured by selecting healthcare professionals and decision-makers from multiple centers. However, to mitigate potential bias stemming from the small sample size, further refinement of the causal loop should include representatives from the remaining Integrated Care Organizations, followed by focus group discussions with patients to ensure their voices and perspectives are heard and considered.

We examined the Basque context and the cultural factors influencing the study. To address the regional limitation, we explored the applicability of these models in diverse cultural and healthcare settings that align with Spanish Hofstede's cultural value dimensions [69]. For instance, countries such as Austria, Costa Rica, Fiji, Honduras, Jamaica, Malawi, Nepal, Panama, Sierra Leone, and Vietnam exhibit moderate scores in long-term orientation. This balance reflects a dual emphasis on preserving traditional values while adapting to modernization and innovation. In these cultures, there is an appreciation for longstanding practices alongside a readiness for progress. Similarly, countries like Bulgaria, South Korea, Turkey, Argentina, Bolivia, Bosnia and Herzegovina, and Chile demonstrate cultural tendencies where strict adherence to rules coexists with a recognition of the stress caused by ambiguity and change. These cultures often avoid confrontation, as it escalates quickly to the personal level, and grapple with the challenges of navigating complex, undefined situations. Thus, the causal loop diagram primarily reflects the Basque context with significant potential for diverse global contexts.

The causal loop diagram primarily reflects the Basque context, but the high-level concepts were contrasted with a literature review considering articles between 2004 and 2021, restricted to English language. The three high-level concepts (talking about death, change towards a holistic and share care model, and HCP's attitude and perspective towards a shared care model) cover three out of the four knowledge areas identified from literature, namely, human, organization, and contextual [70–72]. The technological knowledge area was covered within the organization area in this study. Some challenging factors in implementing the ACP on the causal loop diagram have been reported in previous studies [8, 73–77] which reinforce the general perspective of the results presented here. What this study adds is the system modeling that correlates those challenges and provides a detailed description of the concepts and the influences.

Finally, the qualitative causal loop diagram was primarily derived from stakeholders shared mental models. To test this model, further work on the simulation of the interactions between system elements over time and designing and evaluating potential intervention scenarios would greatly improve understanding of the complexities in collaborative management of knowledge on ACP for multi-morbid patients, within personalized integrated care. Patient perspectives and how they can be integrated into the shared care model could also be explored.

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Author Contribution F.P.T. and A.O. prepared the focus group discussion (FGD) documents and the required materials, took part in data collection and development of causal loop diagrams, and wrote the main manuscript text; N. G., I. E., B.L.P. and D.V. took part in the data collection i.e. prepared FGDs, moderated the focus group sessions, transcribed data and translated the collected information from Spanish to English; A.F. and E.M. contributed to the study's conception, design, identified and contacted healthcare professionals that took part in the FGD, and approved the final manuscript; I.S. and B.Z. verified transcribed data and models with healthcare professionals and provided context of the Basque health system.

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Data Availability No datasets were generated or analysed during the current study.

Declarations

Ethical Approval Ethical approval was deemed 'not applicable' for this study as it did not involve direct patient data collection; however, such approval would be required for conducting surveys and focus groups with patients or when collecting data from discussions centered on individual patient care. The Research Ethics Committee of the Basque Country requires evaluation of a research project in certain cases: when the subjects are patients, when medications or medical devices are being studied, when medical records are reviewed or patient data is collected for research purposes, or when biological samples are used (https://www.euskadi.eus/contenidos/informacion/ayuda_ceic/es_def/adjuntos/Folleto-informativo-CEI.pdf). Since this research does not fall under these conditions, ethical approval was not necessary.

Competing Interests The authors declare no competing interests.

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