INSUFICIÈNCIA CARDÍACA AVANÇADA: IMPACTE DELS DETERMINANTS SOCIALS, EXPERIÈNCIA AMB LA MALALTIA I MODEL DE GESTIÓ D'ATENCIÓ AL PACIENT

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Tesi doctoral

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Memòria presentada per optar al grau de Doctora per la
Universitat Autònoma de Barcelona

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Facultat de Medicina

AGRAÏMENTS

Durant el recorregut d'aquesta tesi, hi ha hagut moltes persones que m'han ajudat i sense elles no hagués estat possible arribar fins aquí.

En primer lloc, agraeixo tota la feina dedicada als meus directors de tesi el Dr. Xavier Castells i la Dra. Anna Berenguera. Ells m'han ensenyat a desenvolupar la recerca sota les metodologies qualitativa i quantitatives i això m'ha donat l'oportunitat d'aprendre sobre diferents perspectives metodològiques. Us vull agrair la paciència i el temps que m'heu dedicat durant tot aquest trajecte.

També vull agrair a tots els membres que formen part de la Unitat de Suport a la Recerca de Barcelona de l'Institut Català de la Salut. Gràcies per tot el suport tècnic que m'heu donat en l'inici de la realització d'aquesta tesi, durant aquest temps vaig descobrir que la recerca era quelcom fascinant.

A tots els investigadors que han format part dels estudis publicats, junt a vosaltres he après el valor del treball en equip i la vostra aportació en cada un dels projectes m'ha ajudat a duu a terme cadascun dels articles. La vostra feina ha estat vital.

A la Dra. Margarita Posso, per tot el que m'ha ensenyat amb una paciència infinita. Per ajudar-me en els moments més durs i per tot el que hem compartit durant aquesta tesi. No puc deixar passar la oportunitat d'agrair-te tot el temps que m'has dedicat, moltíssimes gràcies.

Al Dr. Luis González de Paz, perquè quan el camí es feia molt dur vas arribar per donar-me la darrera empenta. Gràcies pel teu temps i generositat.

A la Sílvia Zamora, directora del Cap Roger de Flor on desenvolupo la meva feina assistencial. Gràcies per recolzar la recerca i per confiar en aquest projecte. El teu suport ha fet que hagi pogut gaudir encara més de tot aquest viatge.

A la Dra. Marta Roqué del centre Cochrane, per la formació i les videotrucades en plena pandèmia aclarint els meus dubtes de la revisió sistemàtica. Gràcies per la teva paciència i per la manera tan aclaridora de resoldre els meus dubtes.

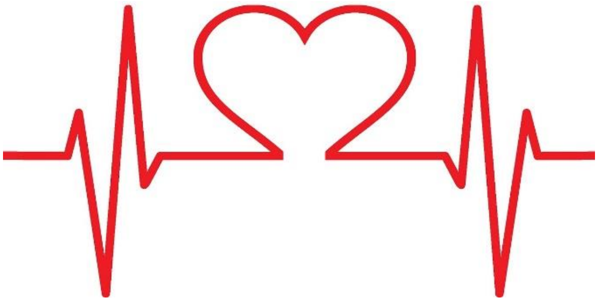
Al Joan Carles Contel del Departament de Salut de Catalunya, gràcies per l’interès que sempre has mostrat en el desenvolupament d’aquesta tesi.

També vull agrair als meus pares i la meva germana pel suport i comprensió durant aquests cinc anys. Gràcies per recolzar-me sempre.

A l’Ariadna, per ensenyar-me que l’amor és infinit i emplenar-me de vitalitat cada dia des del mes d’abril del 2021.

Finalment, vull dedicar aquesta tesi al meu company de viatge. A tu, David, sense tu res d’això hagués pres forma. Gràcies per ser, per deixar-me ser i per recolzar-me en aquest somni.

Les infermeres hem de conèixer les vessants fisiològica i emocional del cor de les persones.



Aquesta tesi ha estat realitzada sota la direcció del Dr. Xavier Castells i la Dra. Anna Berenguera i es presenta com a compendi de publicacions.

FINANÇAMENT

Aquesta tesi ha estat possible gràcies a diferents subvencions:

- Projecte de recerca: “Vivències dels pacients amb insuficiència cardíaca avançada”. Projecte finançat dins la convocatòria “19è Ajut a Projectes de Recerca en Atenció Primària de Salut” de l’IDIAP Jordi Gol i Gurina (4R17/010).

- Projecte de recerca: “Models d’atenció i vivències dels pacients amb insuficiència cardíaca avançada”. Projecte realitzat amb el suport del Departament de Salut de la Generalitat de Catalunya, en la convocatòria corresponent a l'any 2018 de concessió de subvencions del Pla Estratègic de Recerca i Innovació en Salut (PERIS) 2019-2021, dins la modalitat “Subvencions per a la intensificació de l'activitat investigadora de professionals de la salut sense formació sanitària especialitzada”, amb el codi d'expedient SLT008/18/00130.

ÍNDEX

1. RESUM

Introducció

La insuficiència cardíaca (IC) avançada és una malaltia prevalent i amb una alta tassa de mortalitat arreu del món. Existeix una manca coneixement sobre l'impacte del context social en la letalitat de la malaltia, igualment de l'experiència vivencial d'aquest pacients.

Els models de Gestió de Casos (GC) liderats per infermeres han demostrat que impacten en una millora els resultats en salut de les persones amb IC, però manca un major coneixement sobre la cost-efectivitat d'aquests.

Per tant, és rellevant conèixer l'impacte del context social i l'experiència de les persones amb IC avançada i avaluar l'efecte i l'efectivitat de la gestió de casos liderada per infermeres.

Objectius

L'objectiu general d'aquesta tesi és explorar l'impacte del context social i l'experiència de les persones insuficiència cardíaca avançada i avaluar l'efecte i l'efectivitat d'un model de gestió clínica en la fase avançada de la malaltia.

Mètodes

Es van realitzar tres estudis amb diferents perspectives metodològiques. Per avaluar l'impacte del context social en la mortalitat es va realitzar un estudi de cohorts retrospectives amb les dades de les històries clíniques dels pacients amb IC avançada residents a Catalunya. Es van recollir dades clíniques, de dependència per a les activitats bàsiques i el context social entre els anys 2010-2013.

Per conèixer l'experiència de les persones amb IC es va realitzar un estudi qualitatiu a quatre centres d'atenció primària de Barcelona i es van desenvolupar dotze entrevistes en profunditat a pacients amb IC avançada majors de 65 anys i visitats pel seus professionals de salut a domicili. Per obtenir riquesa i variabilitat en el discurs els participants van ser escollits tenint en compte el gènere, l'edat i el nivell socioeconòmic. Per tal d'analitzar les entrevistes el discurs dels pacients es va emmarcar sota el model de Leventhal.

Finalment es va realitzar una revisió sistemàtica per resumir l'efecte i l'efectivitat de la gestió de casos liderada per infermeres on es van explorar els resultats dels articles científics publicats fins el març de 2022 de les bases de dades MEDLINE, CINAHL, Embase, Clinical Trials, WHO, *Registry of International Clinical Trials* i Cochrane Central. Es van fer servir els instruments *Consensus Health Economic Criteria* per determinar el risc de biaix de les avaluacions econòmiques, *Cochrane risk-of-bias 2* pels assajos clínics i una adaptació de *Robins-I* pels estudis quasiexperimentsls i de cohorts. Les dades es van meta-analitzar mitjançant el programa Review Manager i STATA.

Resultats

L'estudi de cohorts va incloure un total de 1148 persones amb IC avançada amb una mitjana d'edat de 82 (DE 9.0) i un seguiment mitjà de 18,2 (11,9) mesos. Un 63,6% presentava risc social i el 9,3% va reconèixer tenir problemes socials. En el model multivariant ajustat es va observar un major risc de mort en cas tenir alta dependència per a les activitats bàsiques de la vida diària (HR, 2,16; IC del 95%, 1,21–3,85) i presentar problema social (HR, 2,46; IC del 95%, 1,22–4,97).

En l'estudi qualitatiu els participants van expressar que la informació que rebien sobre la IC era insuficient i contradictòria. Els pacients van parlar sobre la representació cognitiva i demanaven millorar la comunicació amb els professionals de salut. Les limitacions físiques eren percebudes com a normals degut a l'edat avançada i no com a conseqüència de la IC. Es van observar diferències de gènere en la representació emocional. Les dones es consideraven com a "pilar" en el funcionament familiar i no es sentien útils si no podien correspondre amb les expectatives socials relacionades amb el gènere. La representació cognitiva dels participants incloïa estratègies relacionades amb l'alimentació, medicació, registre del pes i pressió arterial. Tot i això, els pacients percebien el locus de control com a extern i es sentien incapaços d'incidir en la progressió de la IC. El suport social va ser clau per a les persones durant tot el procés.

Per últim, els resultats de la revisió sistemàtica i meta-anàlisi sobre l'impacte de la GC liderada per infermeres en pacients amb IC avançada va mostrar que no va reduir la mortalitat (RR 0,78, IC del 95% 0,53 a 1,15; participants = 1345; estudis = 6; I2 = 47%), en canvi, van disminuir les hospitalitzacions per IC (HR 0,79, IC del 95% 0,68 a 0,91; participants = 1989; estudis = 8; I2 = 0%) i totes les causes (HR 0,73, IC 95% 0,60 a 0,89; participants = 1012; estudis = 5; I2 = 36%). La qualitat de vida va millorar en el seguiment a mitjà termini (diferència de mitjanes estandarditzada (DME) 0,18; IC del 95%: 0,05 a 0,32; participants = 1228; estudis = 8; I2 = 28). Un estudi va mostrar un bon perfil de cost-efectivitat sota una disponibilitat a pagar de 15.000€/AVAQ (costos del 2015).

Conclusions

Els pacients amb IC avançada amb problemàtica social, tenen taxes de mortalitat més altes que els pacients amb millor suport social, independentment de la seva comorbiditat i estat funcional. El suport social és un element clau del punt de vista de la mortalitat i des de l'experiència de vida dels pacients. Existeixen diferències de gènere en la representació emocional. Les dones refereixen més símptomes depressius i els homes es mostren calmats i inclús amb esperança de ser curats. Els pacients senten que la comunicació amb els professionals sanitaris és insuficient

La gestió de casos liderada per infermeres redueix els ingressos hospitalaris i millora la qualitat de vida a mig termini dels pacients. El model de gestió de casos liderat per infermeres podria ser un model cost-efectiu.

1.1 RESUMEN

Introducción

La insuficiencia cardíaca (IC) avanzada es una enfermedad prevalente y con una alta tasa de mortalidad en todo el mundo. Existe una falta de conocimiento sobre el impacto del contexto social en la letalidad de la enfermedad, igualmente de la experiencia vivencial de estos pacientes.

Los modelos de Gestión de Casos (GC) liderados por enfermeras han demostrado que impactan en una mejora los resultados en salud de las personas con IC, pero falta mayor conocimiento sobre su coste-efectividad.

Por tanto, es relevante conocer el impacto del contexto social y la experiencia de las personas con IC avanzada y evaluar el efecto y la efectividad de la gestión de casos liderada por enfermeras.

Objetivos

El objetivo general de esta tesis es explorar el impacto del contexto social y la experiencia de las personas con insuficiencia cardíaca avanzada y evaluar el efecto y efectividad de un modelo de gestión clínica en la fase avanzada de la enfermedad.

Métodos

Se realizaron tres estudios con distintas perspectivas metodológicas. Para evaluar el impacto del contexto social en la mortalidad, se realizó un estudio de cohortes retrospectivas con los datos de las historias clínicas de los pacientes con IC avanzada residentes en Cataluña. Se recogieron datos clínicos, de dependencia para las actividades básicas y el contexto social entre 2010-2013.

Para conocer la experiencia de las personas con IC se realizó un estudio cualitativo en cuatro centros de atención primaria de Barcelona y se desarrollaron doce entrevistas en profundidad a pacientes con IC avanzada mayores de 65 años y visitados por sus profesionales de salud a domicilio. Para obtener riqueza y variabilidad en el discurso, los participantes fueron escogidos teniendo en cuenta el género, la edad y el nivel socioeconómico. Para analizar las entrevistas, el discurso de los pacientes se enmarcó bajo el modelo de Leventhal.

Por último se realizó una revisión sistemática para resumir el efecto y la efectividad de la gestión de casos liderada por enfermeras donde se exploraron los resultados de los artículos científicos

publicados hasta marzo de 2022 de las bases de datos MEDLINE, CINAHL, Embase, Clinical Trials, WHO, *Registry of International Clinical Trials* y Cochrane Central. Se utilizaron los instrumentos *Consensus Health Economic Criteria* para determinar el riesgo de sesgo de las evaluaciones económicas, *Cochrane risk-of-bias 2* para los ensayos clínicos y una adaptación de *Robins-I* para los estudios cuasiexperimentsles y de cohortes. Los datos se meta-analizaron mediante el programa Review Manager y STATA.

Resultados

El estudio de cohortes incluyó a un total de 1148 personas con IC avanzada con una media de edad de 82 (DE 9.0) y un seguimiento medio de 18,2 (11,9) meses. Un 63,6% presentaba riesgo social y el 9,3% reconoció tener problemas sociales. En el modelo multivariante ajustado se observó un mayor riesgo de muerte en caso de tener alta dependencia para las actividades básicas de la vida diaria (HR, 2,16; IC del 95%, 1,21–3,85) y presentar problema social (HR, 2,46; IC del 95%, 1,22-4,97).

En el estudio cualitativo, los participantes expresaron que la información que recibían sobre la IC era insuficiente y contradictoria. Los pacientes hablaron sobre la representación cognitiva y pedían mejorar su comunicación con los profesionales de salud. Las limitaciones físicas eran percibidas como normales debido a la edad avanzada y no como consecuencia de la IC. Se observaron diferencias de género en la representación emocional. Las mujeres se consideraban un “pilar” en el funcionamiento familiar y no se sentían útiles si no podían corresponder con las expectativas sociales relacionadas con el género. La representación cognitiva de los participantes incluía estrategias relacionadas con la alimentación, medicación, registro del peso y tensión arterial. Sin embargo, los pacientes percibían el locus de control como externo y se sentían incapaces de incidir en la progresión de la IC. El soporte social fue clave para las personas durante todo el proceso.

Por último, los resultados de la revisión sistemática y meta-análisis sobre el impacto de la GC liderada por enfermería en pacientes con IC avanzada mostró que no redujo la mortalidad (RR 0,78, IC del 95% 0,53 a 1,15; participantes = 1345; estudios = 6; I2 = 47%), en cambio, disminuyeron las hospitalizaciones por IC (HR 0,79, IC del 95% 0,68 a 0,91; participantes = 1989; estudios = 8; I2 = 0%) y por todas las causas (HR 0,73, IC 95% 0,60 a 0,89; participantes = 1012; estudios = 5; I2 = 36%). La calidad de vida mejoró en el seguimiento a medio plazo (diferencia de medias estandarizada (DME) 0,18; IC del 95%: 0,05 a 0,32; participantes = 1228; estudios = 8; I2 = 28). Un estudio mostró un buen perfil de coste-efectividad bajo una disponibilidad a pagar de 15.000€/AVAQ (costes de 2015).

Conclusiones

Los pacientes con IC avanzada con problemática social, tienen tasas de mortalidad más altas que los pacientes con mejor soporte social, independientemente de su comorbilidad y estado funcional. El soporte social es un elemento clave del punto de vista de la mortalidad y desde la experiencia de vida de los pacientes. Existen diferencias de género en la representación emocional. Las mujeres refieren más síntomas depresivos y los hombres se muestran calmados e incluso esperando ser curados. Los pacientes sienten que la comunicación con los profesionales sanitarios es insuficiente.

La gestión de casos liderada por enfermeras reduce los ingresos hospitalarios y mejora la calidad de vida a medio plazo de los pacientes. El modelo de gestión de casos liderado por enfermeras podría ser un modelo coste-efectivo.

1.2 ABSTRACT

Introduction

Advanced heart failure (HF) is a prevalent disease with a high mortality rate worldwide. There is a lack of knowledge about the impact of the social context on the lethality of the disease, as well as the living experience of these patients.

Case Management (CM) models led by nurses have shown have an impact on improving the health outcomes of people with HF, but more knowledge is lacking about their cost-effectiveness.

Therefore, it is relevant to know the impact of the social context and the experience of people with advanced HF and to evaluate the effect and effectiveness of case management led by nurses.

Objectives

The general objective of this thesis is to explore the impact of the social context and the experience of people with advanced heart failure and to evaluate the effect and effectiveness of a clinical management model in the advanced phase of the disease.

Methods

Three studies were carried out with different methodological perspectives. To assess the impact of the social context on mortality, a retrospective cohort study was conducted with data from the medical records of patients with advanced HF residing in Catalonia. Clinical, dependency data for basic activities and social context were collected between 2010-2013.

In order to explore the experience of people living with HF, a qualitative study was developed in four primary care centers in Barcelona and twelve in-depth interviews were carried out with patients with advanced HF older than 65 years and visited at home by their health professionals. In order to obtain richness and variability in the discourse, the participants were chosen taking into account gender, age and socioeconomic level. To analyze the interviews, the discourse of the patients was framed under the Leventhal model.

Finally, a systematic review was carried out to summarize the effect and effectiveness of case management led by nurses. The results of the scientific articles published up to March 2022 from the MEDLINE, CINAHL, Embase, Clinical Trials, WHO, Registry of International Clinical Trials and Cochrane Central databases were explored. The Consensus Health Economic Criteria

instrument was used to determine the risk of bias of economic evaluations, Cochrane risk-of-bias 2 for clinical trials and an adaptation of Robins-I for quasi-experimental and cohort studies. Data were meta-analyzed using Review Manager software and STATA.

Results

The cohort study included a total of 1148 people with advanced HF with a mean age of 82 (SD 9.0) and a mean follow-up of 18.2 (11.9) months. Social risk was present in 63.6% and 9.3% acknowledged having social problems. In the adjusted multivariate model, a higher risk of death was observed in case of high dependence for basic activities of daily living (HR 2.16; 95% CI, 1.21–3.85) and presenting a social problem (HR 2.46; 95% CI, 1.22-4.97).

In the qualitative study, the participants expressed that the information they received about HF was insufficient and contradictory. The patients talked about cognitive representation and asked to improve their communication with health professionals. Physical limitations were perceived as normal due to advanced age and not as a consequence of HF. Gender differences were observed in emotional representation. Women felt as a 'pillar' in family functioning and did not feel useful if they could not match societal expectations related to gender. The cognitive representation of the participants included strategies related to diet, medication, weight recording and blood pressure. However, the patients perceived the locus of control as external and felt incapable of influencing the progression of HF. Social support was key for people throughout the process.

Lastly, the results of the systematic review and meta-analysis on the impact of nurse-led CM in patients with advanced HF showed that it did not reduce mortality (RR 0.78, 95% CI 0.53 to 1.15; participants = 1345; studies = 6; I2 = 47%), in contrast, HF hospitalizations decreased (HR 0.79, 95% CI 0.68 to 0.91; participants = 1989; studies = 8; I2 = 0%) and for all causes (HR 0.73, 95% CI 0.60 to 0.89; participants = 1012; studies = 5; I2 = 36%). Quality of life improved at medium-term follow-up (standardized mean difference (SMD) 0.18, 95% CI 0.05 to 0.32; participants = 1228; studies = 8; I2 = 28). One study showed a good cost-effectiveness profile under a willingness to pay of €15,000/AVAQ (2015 costs).

Conclusions

Patients with advanced HF and social problems have higher mortality rates than patients with better social support, regardless of their comorbidity and functional status. Social support is a key element from the point of view of mortality and from the life experience of patients. There are gender differences in emotional representation. Women report more depressive symptoms and men are calm and even waiting to be cured. Patients feel that communication with healthcare professionals is insufficient.

Nurse-led case management reduces hospital admissions and improves patients' quality of life in the medium term. The nurse-led case management model could be a cost-effective model.

LLISTAT D'ABREVIATURES

IC	Insuficiència cardíaca
FEVE	Fracció d'ejecció del ventricle esquerre
AVD	Activitats de la vida diària
IECA	Inhibidors del enzim convertidor de l'angiotensina
ARA II	Antagonistes dels receptors de la angiotensina
ARM	Antagonistes dels receptors de mineralcorticoids
USD	Dòlar nord-americà
AP	Atenció Primària
NECPAL	Necessitats Pal·liatives
NYHA	New York Heart Association
DAP	Dispositiu d'assistència ventricular
SNS	Sistema Nacional de Salut
GC	Gestió de casos
CMSA	Case anagement society of America
AVG	Anys de vida guanyats
AVAQ	Anys de vida ajustats per qualitat

2. INTRODUCCIÓ

2.1 LA INSUFICIÈNCIA CARDÍACA

La insuficiència cardíaca (IC) és una síndrome clínica causada per una disfunció del miocardi (sistòlica o diastòlica), per patologia valvular o ambdues. La malaltia pot provocar alguns símptomes (p.e. dificultat per respirar, fatiga) acompanyat d'una sèrie de signes (p.e. edemes a les extremitats inferiors, crepitants pulmonars o pressió venosa jugular elevada) [1].

Les dades epidemiològiques sobre la prevalença i incidència mundial de la IC són escasses i aquestes provenen principalment d'Europa i de Nord-Amèrica, on es registren aproximadament 21 milions de persones afectades [2]. En canvi, existeix poca informació sobre la incidència de la malaltia a l'Àsia i no hi ha dades poblacionals de l'afectació a l'Àfrica septentrional i subsahariana. Les dades de prevalença més actualitzades a nivell mundial corresponen a les de l'estudi de Groenewegen l'any 2020 [3] que es mostren a la Figura 1.

Figura 1: Prevalença mundial d'insuficiència cardíaca.

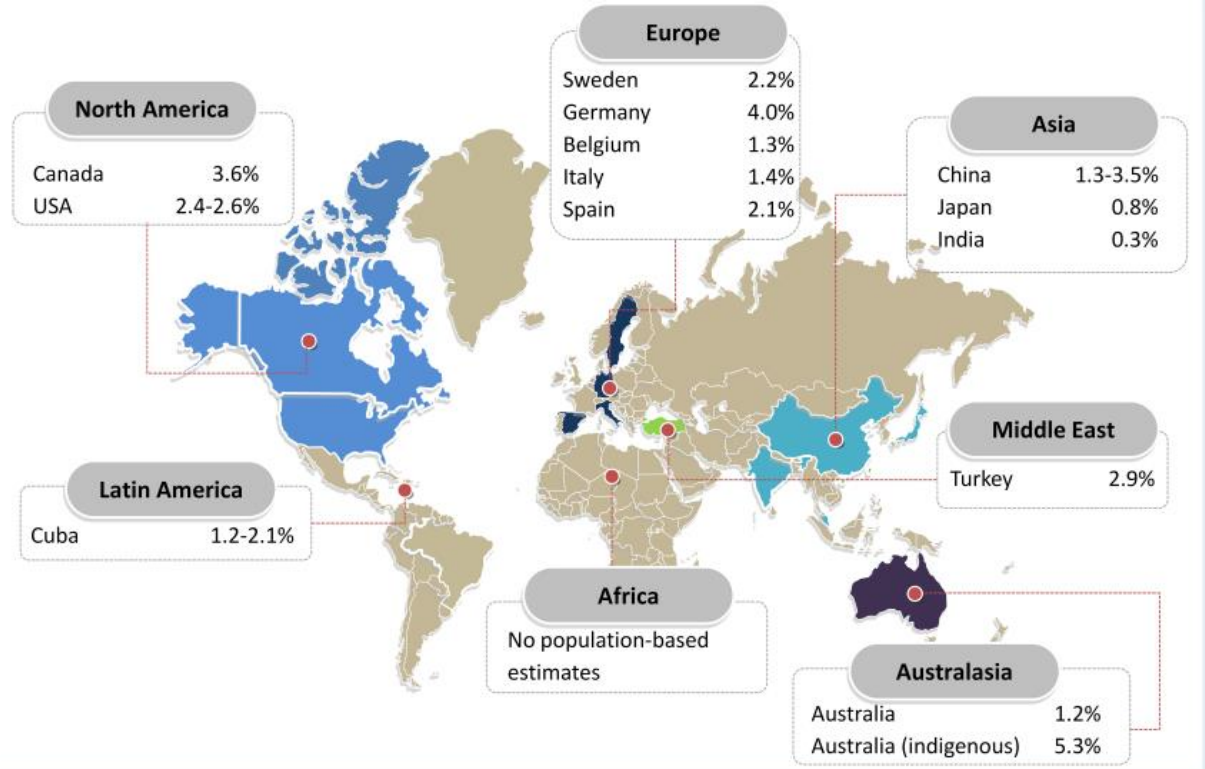


Figure 1 Prevalence of heart failure in population-based studies around the world, in percentage, per region.[17,25,29,39,64–71]

Font: Groenewegen A, Rutten FH, Mosterd A, Hoes AW. Epidemiology of heart failure. Eur J Heart Fail. 2020;22(8):1342-1356. doi: 10.1002/ejhf.1858.

Tot i que la incidència de la IC als països desenvolupats ha millorat en els darrers anys com a reflex d'un millor maneig dels factors de risc cardiovascular, l'increment de l'esperança de vida fa que continuï creixent el número de persones que la pateixen. Segons les darreres dades publicades a la Guia Europea de Cardiologia del 2021, a Europa, la incidència de IC és de 5/1000 persones/any en persones adultes, i la prevalença en aquest continent es situa entre l'1-2% dels adults [1]. Tanmateix, es coneix que la prevalença d'IC es dobla en cada dècada d'edat i es situa al voltant del 10% entre les persones majors de 70 anys [4]. En relació a Espanya, les dades d'incidència es troben en 2,78 casos nous per 1.000 habitants/any i una prevalença del 1,89% de la població [5].

El diagnòstic de la IC és un procés complex que requereix accessibilitat a diferents proves diagnòstiques (electrocardiografia, determinació de pèptids natriurètics en sang, ecocardiografia i sovint, altres proves per cercar possibles comorbiditats). Un cop detectada la malaltia, la classificació de la IC es basa principalment en l'estratificació del pacient segons la mesura de la fracció d'ejecció del ventricle esquerre (FEVE), i en la capacitat funcional que té la persona per desenvolupar les activitats de la vida diària (AVD).

A la guia Europea de la IC del 2021, es va actualitzar la classificació de la IC segons la FEVE classificant els fenotips de la següent manera [1]:

FEVE reduïda: persones amb una FEVE <40%.

FEVE lleugerament reduïda: persones amb una FEVE entre el 40-50%. Els estudis realitzats apunten que el tractament en aquestes persones hauria de ser similar al de les persones amb FEVE <40%.

FEVE preservada: persones amb signes i símptomes de IC però amb una FEVE > o igual al 50%.

D'altra banda, la classificació de la New York Heart Association (NYHA), proposa una terminologia més senzilla, basada en la capacitat funcional de la persona en desenvolupar la seva vida quotidiana. Aquesta classificació no té en compte la FEVE, sinó que emmarca la gravetat de l'individu segons la capacitat que té per desenvolupar el seu dia a dia en els següents termes que s'exposen a la Taula 1:

Taula 1: Classificació funcional segons la New York Heart Association.

Classe funcional I: Sense limitacions en l'activitat. Sense palpitacions, fatiga o dispnea.

Classe funcional II: Lleugera limitació en l'activitat. Activitats del dia a dia desencadenen símptomes de palpitacions, fatiga o dispnea.

Classe funcional III: Activitat física amb alta limitació. Petits esforços desencadenen símptomes.

Classe funcional IV: Símptomes amb qualsevol activitat, inclús poden estar presents en repòs.

Font: Mc Donagh T, MEtra M, Adamo M, Gardner R, Baumbach A, Böhm M, Burri H et al. 2021 ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure. European Heart Journal. 2021;42:3599-3726.

Un cop instaurada la malaltia, les persones conviuen amb períodes d'estabilitat i períodes de descompensació cardíaca (que sovint requereixen d'ingrés hospitalari), fins arribar a la mort de l'individu [6].

2.1.1 LA INSUFICIÈNCIA CARDÍACA AVANÇADA

La European Cardiovascular Society classifica la fase més avançada de la malaltia com aquella que produeix signes i símptomes que no milloren tot i tenir el tractament òptim. Els criteris per patir IC avançada inclouen [1]:

1. Classe funcional III o IV de la New York Heart Association.
2. Signes de disfunció cardíaca severa (ex. FEVE<30%, pèptids natriurètics persistentment elevats, entre d'altres).
3. Episodis de congestió cardíaca que requereixen altes dosis de diürètics o episodis de baix cabal cardíac que requereixen el tractament amb isòtrops o vasoactius i que causen > 1 visita o hospitalització durant el darrer any.
4. Dependència física severa que invalida a la persona caminar >300 metres.

A nivell europeu, entre les persones que pateixen IC, un 26% es troben en la fase avançada de la malaltia [7], en canvi, a Espanya les darreres dades del 2020 apunten valors molt més elevats ocupant el 42% del total de persones amb diagnòstic d'IC [5]. Cal destacar que l'estudi de Sicras-Mainar et al [5], va ser un estudi de registre retrospectiu en el qual la seva mostra estava formada per tots aquells pacients que van cercar atenció sanitària. És possible pensar que les persones que més busquen atenció són aquelles que tenen la malaltia en una fase més avançada ja que tindrien més símptomes associats a la malaltia, i que per tant, aquesta dada podria estar sobreestimada.

Una bona classificació de la malaltia és cabdal per tal de transmetre als pacients i famílies unes expectatives realistes sobre el transcurs de la mateixa i ajustar el pla terapèutic i el tipus de seguiment a les necessitats del moment [8]. En aquest sentit, es reconeix el paper del tractament farmacològic i l'autocura de la persona vers la malaltia com a factors importants en la supervivència de les persones i el bon control de símptomes [1].

A més, tenir cura de persones que pateixen una malaltia crònica com la IC avançada, requereix informar-se i considerar els valors, expectatives i les preocupacions de la persona, ja que aquests podrien influir en el comportament vers la pròpia malaltia [9]. Per tant, la experiència subjectiva de la vivència de la insuficiència cardíaca és rellevant per l'equip de professionals.

Pel que fa als professionals sanitaris que atenen a les persones amb IC avançada, la European Cardiovascular Society especifica que és important que els pacients tinguin un seguiment per part d'un equip multidisciplinari i rebin intervencions específiques amb els objectius de millorar la qualitat de vida, millorar la supervivència i reduir hospitalitzacions i per tant, costos sanitaris associats a aquestes [1]. Un dels models emprats amb aquests objectius és el model de gestió de casos liderat per infermeres [10]. Tanmateix, l'evidència sobre l'efectivitat del model en la IC avançada és controvertida i la seva cost-efectivitat tampoc ha mostrat resultats sòlids.

2.1.2 TRACTAMENT FARMACOLÒGIC

Una bona adherència al tractament farmacològic de la IC, junt amb mesures no farmacològiques, són els factors principals en el bon maneig de la malaltia per tal de millorar la qualitat de vida, la supervivència i les hospitalitzacions per reaguditzacions. Les darreres recomanacions de la European Cardiovascular Society divideixen el tractament farmacològic segons la FEVE del pacient [1]:

- **Pacients amb FEVE reduïda**: Els fàrmacs inhibidors del enzim convertidor de l'angiotensina (IECA), els antagonistes dels receptors de la angiotensina (ARAII), els betabloquejants, els antagonistes dels receptors de mineralcorticoids (ARM), l'inhibidor del cotransportador de sodi-glucosa 2 (dapagliflozina) i els diürètics pautats segons la congestió i símptomes del pacient, han demostrat millorar la mortalitat i les hospitalitzacions de les persones amb IC amb FEVE reduïda.
- **Pacients amb FEVE lleugerament reduïda**: En aquest grup de pacients no existeix evidència sòlida d'assajos randomitzats que demostrin fàrmacs que clarament millorin la mortalitat i els ingressos hospitalaris del pacients. La única recomanació més evidenciada és l'ús de diürètics per tractar la congestió i millorar signes i símptomes. (classe I-C) [11].
- **Pacients amb FEVE preservada**: En aquest grup no existeix evidencia robusta sobre quins fàrmacs millorarien la mortalitat i la morbiditat dels pacients. Dos estudis del grup SENIORS van demostrar bons resultats en l'ús de nevibolol (betabloquejant) en pacients amb FEVE preservada [12,13]. Tot i així, la darrera guia clínica en IC no recomana clarament aquest fàrmac ja que la mostra d'aquests dos estudis no estava composada únicament per pacients amb FEVE preservada. D'altra banda, en els pacients amb FEVE preservada, es recomana el cribratge i seguiment de malalties concomitants i altres comorbiditats, així com l'ús de diürètics per alleujar signes i símptomes congestius (classe I-C).

2.1.3 TRACTAMENT NO FARMACOLÒGIC – AUTOCURA

Segons la infermera teòrica Dorothea Orem, l'autocura és la pràctica d'activitats que realitza l'individu pel seu propi benestar. Dins la seva teoria, podríem considerar que un individu cuida de si mateix si gestiona de manera eficaç el seu procés de malaltia. Aquesta es realitza de manera deliberada i activa, i requereix que la persona sigui capaç d'enraonar i comprendre les seves necessitats de salut [14].

L'autocura de la IC inclou totes les recomanacions d'estils de vida i d'adherència a la medicació que els professionals de la salut donen als pacients. Es coneix que una bona autocura pot millorar la qualitat de vida de les persones [15], disminuir els ingressos hospitalaris i reduir la mortalitat de la IC [16].

Es conegut que durant les descompensacions que provoca la malaltia, les persones acostumen a millorar la manera en que es cuiden, però després de la recuperació, els pacients sovint tenen una tendència a empitjorar l'adherència en relació a les recomanacions indicades pels professionals sanitaris, especialment en relació a l'alimentació i la presa de diürètics [17].

El nivell d'autocura reportat per pacients europeus a través de l'eina *Self-Care of Heart Failure Index* és baix. En una mostra sobre 896 persones, el 47% dels participants van indicar que mai o rara vegada monitoritzaven el seu pes a diari i el 35% va informar que mai o en poques ocasions revisava signes de descompensació cardíaca [18].

S'ha demostrat que hi ha alguns factors que influeixen negativament en l'autocura de les persones amb IC com són; la fragilitat [19], patir depressió [20], tenir demència, prendre digoxina o diürètics de manera crònica (ja que són fàrmacs que es prescriuen en pacients més simptomàtics i per tant, en estadis més avançats de la malaltia), estar en l'estadi IV de la New York Heart Association [21], tenir una baixa acceptació de la malaltia [22], ser home o haver estat hospitalitzat durant el darrer any [23].

D'altra banda, existeixen factors facilitadors associats de manera independent a una bona autocura com són el nivell educatiu i l'educació prèvia sobre la malaltia [24], fet que posa de relleu la importància del rol dels professionals sanitaris vers l'educació sanitària de la malaltia.

La comunicació i la relació professional-pacient, és fonamental per tal d'aconseguir una bona autocura en relació a la IC [25]. En aquest sentit, la European Cardiovascular Society recomana la creació d'equips multidisciplinaris [1] amb formació en IC per tal de reduir el riscs d'hospitalització i millorar la mortalitat dels pacients. En canvi, no existeix informació clara sobre quins són els professionals que haurien de formar part i quina atenció seria més adequada (visites a domicili, visites a un centre, etc), per tant, coexisteixen en l'actualitat diferents models d'atenció vers al pacient amb IC.

A grans trets, la European Society of Cardiology recomana que en aquests equips es treballin sis grans temes amb el pacient durant les visites que es resumeixen a la Taula 2.

Taula 2: Recomanacions per a professionals sanitaris vers el seguiment de pacients amb insuficiència cardíaca.

Tema a tractar	***Descripció del tema***
Educació de la IC	Explicació sobre què és la IC i la seva evolució natural.
Medicació	Explicació sobre la indicació de cada principi actiu, beneficis, necessitat de prendre medicació de manera crònica i efectes adversos més comuns.
Autocura	Recomanació d'activitat i exercici segons la capacitat de la persona. Importància del descans per a la bona salut cardiovascular.
Educació	Evitar beure grans volums de líquid. Pot estar aconsellat una restricció fins a 1.5-2l/dia en pacients amb IC severa. Evitar >5gr de sal/dia. Evitar alcohol. Recomanar vacunació de la grip i del pneumococ. Evitar tabaquisme. Adaptar les relacions sexuals al nivell d'activitat física tolerat. Monitoritzar símptomes i signes de descompensació i saber com i quan contactar amb els professionals de salut.
Viure amb IC	Reconèixer quan buscar ajuda psicològica si símptomes depressius, ansietat o tristesa. Reconèixer que la família i/o cuidadors poden tenir necessitat de buscar suport psicològic.
Família i cuidadors	Ser capaç de demanar ajuda a la xarxa social de la persona.

Font: Mc Donagh T, MEtra M, Adamo M, Gardner R, Baumbach A, Böhm M, Burri H et al. 2021 ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure. European Heart Journal. 2021;42:3599-3726.

Es considera molt rellevant el paper que tenen els professionals de salut en l'ajuda de l'autocura de les persones amb IC, ja que tenen un paper facilitador d'informació i recomanacions relacionades amb la malaltia amb la potencialitat de millorar la qualitat de vida i prevenir descompensacions cardíaques.

2.2 COSTOS ASSOCIATS A LA INSUFICIÈNCIA CARDÍACA

Per entendre la magnitud del problema de la IC, cal parlar dels costos que suposa a la societat atendre a les persones que pateixen la malaltia. Els estudis que existeixen fins l'actualitat, han reportat els costos relacionats amb la IC de manera generalitzada i no existeixen estudis específics sobre els costos de la IC en la fase més avançada. Pet tant, els costos que s'exposen en aquest apartat d'aquesta tesi, pertanyen a aquells relacionats de manera general amb la malaltia i no específicament amb la IC avançada. Es podria inferir, que els costos en la IC avançada seran majors degut a que el cost de la malaltia augmenta a mesura que la IC avança principalment per la discapacitat que provoca en la persona i l'augment de necessitats de tractament, hospitalitzacions i abordatges més intensius per part dels professionals de la salut [26].

Dins els costos que suposa la malaltia, el tractament hospitalari dels pacients amb IC comporta la major càrrega econòmica, responsable d'aproximadament la meitat del cost directe, seguit dels costos derivats de l'atenció per part dels professionals de primària i els fàrmacs. A nivell mundial, la major part dels estudis publicats en la relació dels costos s'han desenvolupat en països occidentals amb alts ingressos. Hi ha una manca de coneixement sobre els costos relacionats amb la malaltia en països d'ingressos mitjans i baixos, tot i que aquests territoris representen més del 80% de població mundial. Podem considerar que actualment l'estudi de costos no és una prioritat per aquests països i d'altra banda podrien no disposar de dades administratives per reportar-los de manera àgil [27].

Als EEUU, un estudi va concloure que els costos directes de la IC durant la vida de la persona eren de 126.819 $ per pacient i va situar la càrrega econòmica al voltant del 1-2% del pressupost sanitari al país [28]. Tanmateix, el cost global per a la nació tenint en compte els costos indirectes de dies de feina perduts es situava en 30.7 $ mil milions [29].

A nivell europeu, els estudis han mesurat els costos de diferent manera, tenint en compte costos directes i/o indirectes. A Dinamarca, els costos directes i indirectes per pacient i any van ser de

17.039€ el 2016 [30]. Suècia, va reportar costos directes de 12.890€ per pacient i any el 2019 [31] i en el cas d'Espanya, es van reportar 2.770€ per pacient i any el 2019 [32].

Un estudi realitzat a Alemanya i Àustria reporta els costos més baixos a Europa, i s'estima un cost directe anual de 1.188€ per pacient l'any 2011. Tot i així, és important destacar que en aquest cas només el 14,7% dels participants van ingressar a l'hospital, i que probablement per aquesta raó, el cost global va ser significativament inferior a altres països europeus.

Fora de l'entorn europeu, la variabilitat dels costos de salut és alta, una revisió de la literatura a l'Àsia publica costos en diferents països del continent que van des de 3.219USD anuals a Malàsia l'any 2015, fins a 13.071USD anuals a Corea del Sud [33]. En els estudis de costos, els criteris d'inclusió i el context de cada país podrien explicar en gran mesura les variacions en els resultats.

Pel que fa als costos indirectes, hi ha pocs estudis que reportin aquesta informació de manera acurada. A Portugal s'ha estimat que els pacients amb IC suposen un cost indirecte anual de 106 milions d'euros l'any 2014 (16% per absentisme i 84% per reducció d'ocupació) [34] i al nostre entorn s'ha estimat que el cost indirecte dels cuidadors familiars dels pacients amb IC ocupen dos terços del cost global de la malaltia [35]. Per tant, la IC a més de la pèrdua de qualitat de vida que comporta, suposa una condició amb una forta càrrega econòmica i social pel país.

2.3 MORTALITAT

A nivell general, el Global Burden of Disease Study l'any 2017 va estimar 17,7 milions de morts a causa de malalties cardiovasculars a tot el món [36].

Establir quina és la mortalitat concreta de la insuficiència cardíaca és complex ja que la malaltia acostuma a ser conseqüència d'una afectació subjacent (p.e cardiopatia isquèmica o malaltia arterial coronaria) i sovint, es fa servir aquesta afectació com a causa de la mort [37]. D'altra banda, la mortalitat que presenta la IC depèn de diversos factors individuals (p.e. nivell socioeconòmic, ètnia) i de recursos de l'entorn (accessibilitat a recursos sanitaris, protocols…). En aquest sentit, es coneix que les persones que viuen en entorns rurals poden tenir una mortalitat més elevada [38].

Als EEUU al 2018, el 13,4% del total dels certificats de mort van fer referència a la insuficiència cardíaca [39]. En el cas d'Espanya, el 10,9% de la mortalitat global del país va ser atribuït a la IC durant el transcurs dels anys 1999-2013 [40].

Pel que fa a la mortalitat un cop instaurada la malaltia, a nivell europeu, presenta una letalitat al volant del 7% en un any [7] i dades obtingudes al nostre país en pacients amb IC durant el transcurs d'un any, apunten valors de mortalitat que arriben al 14,5% en persones amb IC que precisen d'ingressos hospitalaris per descompensació cardíaca [41], situació que és molt comú en pacients amb IC avançada.

2.4 DETERMINANTS DE MORTALITAT DE LA INSUFICIÈNCIA CARDÍACA AVANÇADA

Amb la finalitat de detectar necessitats de final de vida dels pacients amb IC avançada, adaptar el tractament i generar unes expectatives realistes a persones de l'entorn del malalt, s'han dut a terme diverses estratègies. Una d'elles va ser l'anomenada "pregunta sorpresa" adaptada a l'atenció primària (AP) que incloïa l'instrument NECPAL (Necesitats Pal.liatives) [42] creat l'any 2017. Aquest instrument desenvolupat per l'observatori QUALY-Centre Col·laborador de la OMS per a Programes Públics de Cures Pal·liatives (CCOMS-ICO) amb el recolzament de la Direcció General de Regulació, Planificació i Recursos Sanitaris del Departament de Salut (Generalitat de Catalunya) pretén identificar als malalts amb necessitats pal·liatives. La pregunta sorpresa tracta de que el professional de salut contesti una pregunta generalista sobre la opinió de la expectativa de vida del pacient basada en uns criteris clínics:

Us sorprendria que aquest pacient morís en els propers 12 mesos?

Els criteris clínics per a valorar la malaltia cardíaca són:

- Insuficiència cardíaca NYHA estadi III o IV, malaltia valvular severa o malaltia coronària extensa no revascularitzable.
- Dispnea o angina de repòs o a mínims esforços.
- Símptomes físics o psicològics de difícil maneig, malgrat el tractament òptim ben tolerat. En cas de disposar d'ecocardiografia: fracció d'ejecció severament deprimida (< 30%), hipertensió arterial pulmonar severa o pressió arterial pulmonar sistòlica > 60 mmHg.

- Insuficiència renal associada (FG < 30 l/min)
- Ingressos hospitalaris amb símptomes d'insuficiència cardíaca/cardiopatia isquèmica, recurrents (> 3 darrer any)

Tot i que aquesta eina no va ser creada per predir la mortalitat de les persones, s'ha detectat que en el 73% de les vegades pot predir la mortalitat a l'any [43]. En aquest sentit, el NECPAL ha mostrat una sensibilitat del 85% en la identificació de persones amb IC que estan al final de la vida [44], i per tant, es podria considerar un punt de partida per a la discussió amb el pacient sobre la planificació futura de l'atenció sanitària. Cal tenir en compte que aquests estudis s'han fet amb la població general amb IC en tots els estadiatges i es desconeix la seva predictibilitat en el subgrup de població amb IC avançada.

Aquest desconeixement també queda patent en les discordances que tenen, en la majoria de les ocasions professionals i pacients respecte el pronòstic de la IC avançada. S'ha mostrat que generalment, existeix discrepància entre les opinions de pronòstic entre metges de família i pacients, sent els pacients més optimistes respecte la seva esperança de vida [45]. Aquest fet és important des del punt de vista de la planificació del final de vida, ja que els pacients podrien no veure la necessitat de parlar sobre aquest tema degut a la percepció optimista respecte el seu futur.

Indicadors clínics de mortalitat

Existeixen múltiples estudis que han intentat donar resposta a quins factors prediuen la mortalitat de les persones que pateixen IC, en canvi, existeix menys informació vers el subgrup de població de IC avançada. La informació sobre els factors de risc que es coneix actualment s'exposa de manera resumida a la Taula 3:

Taula 3: Indicadors clínics de mortalitat en la insuficiència cardíaca i la insuficiència cardíaca avançada.

Indicadors de mortalitat per a la IC	**Indicadors de mortalitat per a la IC avançada**
Edat [7]	Fracció d'ejecció reduïda [49,50]
Classe funcional NYHA III o IV [7]	Hipotensió [50]
Malaltia renal crònica [7]	Ús de bolquers [50]

Pressió arterial sistòlica baixa [7]	
Taquicardia [7]	
Índex de massa corporal baix [7]	
No prescripció de betabloquejants [46]	
Albúmina sèrica <3,2 g/dl [47]	
Pèptid natriurètic pro-cerebral N-terminal (NT-proBNP) >5.000 pg/dl [47]	
No diagnòstic d'hipertensió [47]	
Fragilitat [48]	

A banda de la fracció d'ejecció reduïda, hipotensió o utilització de bolquers com a factors de risc que augmenten la probabilitat de mort, no es coneixen més estudis robusts sobre la predicció de mortalitat en el subgrup de població de IC avançada. Alguns autors, han estudiat la IC en fase avançada tenint en compte algunes especificacions que fa que el grup de pacients probablement difereixi de la resta de població amb d'IC avançada. Aquestes especificacions són estudis on la població d'IC avançada compleix criteris per realitzar un trasplantament cardíac, o bé, pacients que disposen d'un dispositiu d'assistència ventricular (DAP).

Tant en els pacients candidats per a trasplantament cardíac com aquells que disposaven d'un DAP, es va demostrar que la **fragilitat** era un factor predictor de mortalitat [51,52]. En canvi, els valors analítics relacionats amb els pèptids natriurètics, van donar resultats diferents per aquestes dues poblacions, sent el **NT-proBNP** un valor predictiu de mortalitat en els pacients candidats a trasplantament cardíac, a diferència del valor NP (pèptid natriurètic), que no va tenir cap implicació en la mortalitat dels pacients que disposaven de un DAP. Es considera que aquestes poblacions tenen característiques particulars i que podrien tenir una potencial milloria clínica amb la utilització del DAP i/o transplantament i això difereix del grup de població amb IC avançada, on la malaltia es troba en situació final, i per tant, els factors predictors trobats no es considerarien extensius a tota la població amb IC avançada.

Amb l'objectiu de predir el risc de mortalitat de manera més acurada i tenir en compte diferents mesures clíniques i fàrmacs, l'any 2020 es va publicar la calculadora més actualitzada per part de l'equip de Simpson et al (http://www.predict-hf.com/) per predir la mortalitat dels pacients amb IC. Aquesta calculadora té en compte principalment variables clíniques, va ser validada a nivell extern amb bona fiabilitat [53]. En canvi, dins Europa hi ha una alta heterogeneïtat en la disponibilitat de proves diagnòstiques. Al nostre entorn i dins la atenció primària (AP), no tenim accessible algunes mesures que proposa aquesta eina com és la mesura del NT-proBNP o el BNP, fet que dificulta la utilització d'aquestes eines i per tant, desconeixem la seva utilitat a la pràctica assistencial.

Altres factors relacionats amb la mortalitat-determinants socials de salut

A banda dels factors clínics predictors de mortalitat, s'han estudiat altres factors relacionats amb com les persones cuiden d'elles mateixes, i en aquest sentit, un nivell baix **d'autocura** ha demostrat ser un factor predictor de mortalitat al nostre entorn. Concretament, s'ha demostrat que la utilització de la escala europea d'autocura (European Heart Failure Self-care Behaviour Scale 9-item) era un predictor independent de mortalitat per totes les causes i esdeveniments cardiovasculars [54]. Aquesta troballa es considera rellevant des del punt de vista de la AP, ja que la eina és accessible en el nostre entorn, és fàcil d'utilitzar i està estandarditzada en el seguiment de pacients amb IC.

És possible que les condicions i les circumstàncies en les que les persones amb IC avançada viuen, el lloc on resideixen, aprenen i l'afecte que reben dels altres, tingui un impacte en la salut i en la mortalitat dels mateixos [55]. L'estudi dels determinants socials de salut inclou diversos components com l'**educació**, el **lloc de naixement**, la **migració**, el **barri on es viu**, **l'habitatge** i la **posició econòmica**, entre d'altres [56].

Els pacients amb IC avançada acostumen a necessitar més ajuda en el seu dia a dia i per tant, els determinants socials de salut tenen un paper més predominant que en altres fases de la malaltia. Es coneix que la inestabilitat econòmica, el lloc de residència i el context comunitari i social desfavorable, augmenten el risc de malalties cardiovasculars [57,58]. A més, les **relacions socials** juguen un paper clau en la experiència de vida de les persones amb IC i el nivell socioeconòmic té un impacte directe sobre la mortalitat [59] i la qualitat de vida de la població amb IC en tots els seus estadiatges de la NYHA [60].

En canvi, no es coneix quin efecte produeixen els determinants socials de salut sobre la població amb IC avançada vers la mortalitat. És possible pensar que la acumulació de determinants socials desfavorables, poden conduir a una situació de risc social i aquest, a un augment del risc de mortalitat. Els estudis fins al moment s'han basat en la població amb IC general i no hi ha documentació sobre l'impacte que té en els pacients amb IC avançada.

A Catalunya, el sistema nacional de salut (SNS) va implementar un programa de seguiment de pacients amb IC liderat per infermeres [61]. Aquest programa inclou l'avaluació del risc social del pacient atès a la comunitat, mitjançant l'anàlisi de la situació familiar, condicions d'habitatge, situació econòmica, relacions socials i suport social [62].

Degut a que no existeix evidència sobre l'efecte dels determinants socials sobre la IC avançada, i que aquests determinants s'han considerat de manera aïllada als estudis fins al moment, un dels objectius d'aquesta tesi doctoral és determinar l'impacte del risc social en la mortalitat dels pacients amb IC avançada a l'entorn de l'atenció primària de salut.

2.5 LA PERSPECTIVA DEL PACIENT EN LA INSUFICIÈNCIA CARDÍACA AVANÇADA

Tenir cura de persones que pateixen una malaltia crònica com és la IC avançada, requereix informar-se i considerar els valors i les preocupacions de la persona, ja que aquests podrien influir en el comportament vers la pròpia malaltia [9]. Per tant, la experiència subjectiva de com viuen les persones la insuficiència cardíaca és rellevant per als professionals sanitaris.

Els estudis realitzats fins ara s'han desenvolupat majoritàriament en població amb insuficiència cardíaca en totes les fases de la malaltia i existeix menys informació relacionada amb la vivència dels pacients amb IC avançada. La Taula 3 recull un breu resum dels factors que contribueixen a un deteriorament de la qualitat de vida i els mecanismes d'adaptació més comuns en la IC.

Taula 3. Símptomes que empitjoren la qualitat de vida de les persones amb insuficiència cardíaca i mecanismes d'adaptació.

Símptomes relacionats amb la IC	**Mecanismes d'adaptació a la IC**
Dispnea	Reestructuració de les expectatives de vida
Cansament/fatiga	Capacitat de resiliència*
Edema a extremitats inferiors	Recolzament social∞
Dificultat per a la realització de les activitats de la vida diària (limitació física)	Seguretat econòmica∞

Depressió	Accés a l’atenció sanitària∞
Ansietat	Consciència de la malaltia*
	Capacitat per buscar ajuda*

*Factors intrínsecs, ∞Factors extrínsecs

Símptomes relacionats amb la malaltia

Els pacients amb IC han descrit símptomes en el seu dia a dia com són la **dispnea, el cansament o l’edema a extremitats inferiors**, que comporten una limitació per poder desenvolupar les seves activitats quotidianes. Entre aquests símptomes, es coneix que la dispnea és el més comú per als pacients, i aquest, produeix una limitació física important en la vida diària de les persones [63].

Aquesta **limitació física** afecta principalment a la deambulació, a romandre en bipedestació durant períodes llargs i contribueix a la dificultat per agafar objectes pesats. Els mecanismes d’adaptació que utilitzen les persones inclouen el descans o l’abstenció de la activitat [64]. Aquesta abstenció vers activitats quotidianes també s’ha descrit en altres àmbits com són les relacions socials. La pròpia limitació física podria fer que les persones tinguessin dificultats en relacionar-se fora de l’entorn domiciliari, fet que comporta un deteriorament de la qualitat de vida de les persones i podria contribuir negativament als problemes de salut mental descrits pels pacients com són la depressió o l’ansietat [65].

Tot i la limitació en les activitats de la vida diària pels símptomes que presenta la malaltia en la fase més avançada, s’ha trobat que els pacients podrien estar tenint una percepció falsament optimista respecte al futur de la IC [66], fet que pot retardar parlar sobre el final de vida amb els professionals sanitaris. Un estudi en pacients amb IC avançada va trobar que només el 5,3% de pacients del total de la mostra de l'estudi havien fet un pla de decisions anticipades [67]. Tenint en compte que aquests es trobaven en situació de final de vida, aquesta dada posa de relleu la necessitat de tenir converses sobre les necessitats dels pacients en aquesta etapa. A més, una revisió d’articles qualitatius en pacients que tenien malalties cròniques avançades conclou que un dels temes més repetits entre els pacients va ser que no es sentien com a part involucrada en la planificació de les cures avançades [68].

Estat emocional

Tot i que els pacients perceben el tractament com a eina per tal d’evitar una descompensació i viure una vida de la manera més independent possible [69], continuen trobant-se amb situacions de descompensacions cardíaques inesperades; s’ha descrit que les persones amb IC senten **incertesa** sobre l'evolució de la mateixa malaltia, fet que de vegades fa que es sentin “sobrepassats” amb la situació en la que viuen [70].

L’estat emocional junt a les limitacions físiques que provoca la malaltia, podrien desencadenar **ansietat i/o depressió**, i per tant, fer que les persones tinguessin una pitjor qualitat de vida [71]. En persones joves existeix un impacte negatiu en la seva trajectòria de vida, en la criança de fills o en la planificació de la jubilació. Viure amb IC suposa reestructurar els objectius de les persones dins la seva trajectòria vital [72].

Mecanismes d’adaptació i relació amb els professionals de la salut

D’altra banda, també s’ha descrit que l’adaptació i la **reestructuració** de les expectatives de vida, pot fer que les persones amb IC percebin una bona qualitat de vida [73]. En aquest sentit, es considera important que les persones tinguin la informació necessària sobre quina és la trajectòria esperable de la malaltia. Adaptar les expectatives de vida a cada moment serà vital per a que les persones amb IC tinguin la millor qualitat de vida possible.

Per contra, una resposta emocional negativa a la malaltia sovint s’ha relacionat amb persones que tenen dificultats per canviar l’estil de vida, dificultats econòmiques, manca de coneixements sobre l’alimentació adequada per a la IC o la manca de confiança en si mateixos per assolir un bon nivell d’activitat física [74]. Això podria produir més descompensacions cardíaques i per tant, generar possiblement una resposta negativa encara major, entrant en un cercle difícil de gestionar.

S’han identificat factors intrínsecs i extrínsecs en els pacients per tal de millorar la capacitat de cuidar-se d’ells mateixos. Els factors intrínsecs estan relacionats amb la **capacitat de resiliència** de les persones, la **consciència** que tenen sobre la situació i la **capacitat per buscar ajuda**. D’altra banda, els factors extrínsecs estan modelats per l’entorn i depenen de la **seguretat econòmica** dels pacients, el **recolzament social** i l’**accés a l’atenció sanitària** [75].

Pel que fa a la relació dels pacients amb els **professionals sanitaris** s’ha trobat que es basa principalment en el tractament curatiu, com tractar les descompensacions en un futur i en l’interès dels pacients per parlar sobre temes de final de vida [76].

Els estudis més recents en la població amb IC avançada s’han basat en explorar les experiències d’alguna intervenció sanitària (com és la telemonitorització) [77] i principalment tenen l’objectiu de trobar la manera de millorar l’autocura dels pacients [78]. En canvi, no existeixen estudis recents al nostre entorn que avaluïn com és l’experiència viscuda de les persones amb IC avançada al seu dia a dia i quines són les seves necessitats.

Cuidar de pacients que pateixen una malaltia crònica com és la IC avançada, requereix conèixer els valors i preocupacions de les persones, ja que aquestes poden influir en el curs de la malaltia [9]. Per aquest motiu, un dels objectius d’aquesta tesi és explorar, des de la perspectiva fenomenològica, les experiències dels pacients amb IC avançada, atesos al domicili en l'entorn de l’atenció primària de salut a la ciutat de Barcelona, per tal d’entendre quina és l’experiència viscuda des d’una perspectiva holística.

2.6 LA GESTIÓ DE CASOS

El concepte de gestió de casos (GC) més conegut i adaptat als diferents entorns és el definit per la Case Management Society of America (CMSA) dels Estats Units. Aquesta societat va ser impulsada per la representant de comptes de la farmacèutica Caremark a EEUU, Lisa Garvey; l’any 1989. Durant la seva trajectòria professional, va promoure la unió de diferents professionals que treballaven com a gestores de casos amb la voluntat d’associar-se, definir i continuar expandint la figura al territori del país [79].

La gestió de casos segons la CMSA tracta d’un model de “col·laboració, planificació, facilitació, coordinació de l’atenció, avaluació i defensa d’opcions i serveis, per tal de satisfer les necessitats de salut de l’individu i de la família mitjançant la comunicació i els recursos disponibles per promoure la seguretat del pacient, la qualitat de l'atenció i la cost-efectivitat” [80]. D’aquesta manera, la gestora de casos ajuda a promoure el benestar i l’autonomia de les persones identificant els proveïdors de recursos i instal·lacions més apropiades per a la situació de cada pacient. La definició de la CMSA no especifica quin és el professional que pot desenvolupar aquest rol i únicament puntualitza que serà un professional que certifiqui que té la suficient formació, capacitats i experiència per prestar els serveis apropiats basant-se en els principis de la pràctica.

El model de GC es porta a terme en múltiples situacions on les persones pateixen malalties cròniques (p.e salut mental o patologia pulmonar crònica) [81,82] i en el que el pacient precisa d’una atenció i coordinació especial ja que el control de la seva malaltia requereix el seguiment per diferents professionals de la salut que presten el seu servei sovint en diferents unitats especialitzades. A més, és comú que els pacients prenguin múltiples fàrmacs que requereixin una bona adherència i que també la persona necessiti un seguiment estret en relació a recomanacions sanitàries vers estils de vida (p.e alimentació o exercici físic). Tanmateix, degut a la complexitat que presenten els pacients amb patologia crònica, és comú que aquests pateixin ingressos hospitalaris no previstos per tractar descompensacions de la seva malaltia. Així doncs, la figura de la GC acompanya en tot el procés al malalt actuant com a coordinadora de l'atenció al pacient dins el sistema sanitari i facilitant els recursos més adients en cada situació.

És conegut que les infermeres tenen un paper en el seguiment dels pacients que presenten complexitat per la seva multimorbiditat [83]. El seguiment que realitzen les infermeres identificant símptomes de descompensació i implementant estratègies per prevenir un major deteriorament físic i mental és crucial per millorar l'estat de salut de les persones [84]. Els models d'atenció al pacient crònic estan principalment liderats per les infermeres [85], fet que és rellevant alhora de decidir quin professional podria portar a terme el rol de gestió de casos.

A Catalunya, el model de GC liderat per infermeres va ser descrit per un grup de Treball del Institut Català de la Salut l'any 2010 com un abordatge integral en les situacions de complexitat, dependència i fragilitat desenvolupant pràctiques avançades i donant resposta a les necessitats de la població. De la mateixa manera, la infermera GC seria la figura d'enllaç entre els diferents nivells assistencials. Així doncs, la infermera GC treballa amb pacients amb multimorbiditat i una elevada fragilitat. Aquest model marca objectius en termes de millora de la qualitat de vida de les persones i eficiència en la utilització de recursos [86].

Pel que fa a les persones amb insuficiència cardíaca avançada, el seu seguiment estret és important per tal de reduir les descompensacions cardíaques evitables i millorar la qualitat de vida. Els pacients en aquest estat poden patir dolor, angoixa, dispnea i nàusees entre d'altres símptomes incapacitants que minven la qualitat de vida. Una bona atenció és essencial per poder tractar els símptomes i millorar les descompensacions. En aquest sentit, l'entorn de l'atenció primària podria tenir les millors característiques pel tractament d'aquests pacients a domicili ja que es coneix que l'entorn domiciliari afavoreix el control dels símptomes per sobre de l'entorn hospitalari [87,88], probablement degut a que el pacient es troba en el seu context. En aquest aspecte, la gestió de casos liderada per infermeria en l'entorn comunitari podria ser un model amb un impacte en la millora de la qualitat de vida de les persones amb IC avançada.

2.6.1 EFECTIVITAT DE LA INTERVENCIÓ DE GESTIÓ DE CASOS

L'efectivitat de la gestió de casos en els pacients amb IC és controvertida. Un estudi que analitza l'efectivitat de la intervenció en la IC avançada basant-se en les característiques de la GC (intervencions domiciliaries, visites ambulatòries, telemonitorització o trucades de seguiment), conclou que els resultats són controvertits respecte l'efecte en la disminució de la mortalitat i el número de reaguditzacions que pateixen les persones amb IC. A més, apunta a que caldria analitzar els costos d'aquests programes per valorar la seva aplicació. Així doncs, la GC podria ser utilitzada en alguns casos concrets però posa en dubte la seva aplicació a tots els pacients amb IC independentment de la fase de la malaltia en el que es troben [89]. De la mateixa manera, altres fonts de la literatura denoten controvèrsia (resultats amb conclusions oposades) en l'efectivitat en termes de mortalitat i hospitalitzacions [90].

En canvi, també es coneix que els pacients en seguiment pel model de GC poden presentar una major adherència i taxes d'hospitalitzacions significativament més baixes. No obstant, dins aquest model d'atenció dissenyat per al seguiment de pacients amb IC, existeixen múltiples visites a metges a una clínica especialitzada [91], i per tant, no es tractaria de la realitat de la GC liderada per infermeres a l'entorn comunitari.

Altres estudis s'han centrat en comprovar si el fet de que els pacients vagin a urgències o hospitalitzin per una descompensació té un efecte positiu en l'adherència a pesar-se com a part del control de la IC. En aquest sentit, s'ha comprovat que l'ingrés hospitalari fa que existeixi una millor adherència als 6 mesos de seguiment [92]. Es plausible pensar que aquest efecte es podria perdre a llarg termini si no existeix un seguiment estret per part de professionals sanitaris com podria ser el cas de la gestió de casos.

Entre les intervencions estudiades cal destacar el treball realitzat pel grup Cochrane de Takeda et al l'any 2019, en que van fer una revisió de l'efectivitat de diferents programes en població amb IC. Aquests programes incloïen: **gestió de casos**, intervencions ambulatòries i intervencions multidisciplinàries. Les intervencions podien ser liderades per qualsevol professional i la població a la que anava dirigida eren aquelles persones amb IC independentment del seu estadiatge segons la NYHA. Aquesta revisió conclou que la GC podia reduir la mortalitat per totes les causes i els reingressos hospitalaris, en canvi, no va haver prou evidència per concloure quin efecte tenia la intervenció sobre la qualitat de vida de les persones [93].

Pel que fa a l’evidència relacionada amb la **GC liderada per infermeres** al nostre país, un estudi recent a la Gran Canaria va realitzar un seguiment en una cohort durant un període de 8 anys en pacients pluripatològics i va concloure que els pacients havien millorat el seu estat de salut i es van reduir els ingressos hospitalaris [94]. Tot i els resultats positius, l’estudi de Duarte-Climents [94] analitza el programa habitual que s’utilitza a la comunitat autònoma de gestores de casos a tota la població de pacients pluripatològics i per aquest motiu, no especifica quins objectius concrets tenien les visites ni quin patró de visites seguien les infermeres gestores de casos (freqüència de visites, contingut d’aquestes etc), fet que pot limitar la interpretació dels seus resultats.

Degut a la heterogeneïtat que pot adquirir la intervenció de **GC liderada per infermeres**, definir quines característiques té el model i la intensitat en la que es realitza (número de visites i temes tractats) es considera clau per poder descriure l’efectivitat de la intervenció en els pacients. Es coneix, per exemple, que un algoritme de dosificació de diürètics dins un programa de telemonitorització liderat per infermeres, pot contribuir a reduir les hospitalitzacions dels pacients amb IC [95]. Informació tan concreta com aquesta pot ajudar a elaborar models d’atenció amb les característiques adients per millorar la seva efectivitat.

Tot i les evidències exposades anteriorment sobre l'efectivitat dels programes de les infermeres GC en els pacients amb IC, la evidència no és concloent i presenta contradiccions. A més, la IC avançada te característiques diferents als estadiatges més inicials de la malaltia, és per això que la GC podria tenir un impacte diferent dins aquest subgrup de pacients. En aquest sentit, un dels objectius d’aquesta tesi és conèixer l’efectivitat de la GC liderada per infermeres en els pacients amb IC avançada.

2.6.2 COST I COST-EFECTIVITAT DE LA GESTIÓ DE CASOS

Tal i com van mencionar anteriorment els autors Gorthi et al [89], és important determinar el cost i la cost-efectivitat de la intervenció de la GC en els pacients amb IC per tal de valorar la incorporació de models de gestió de casos. En aquest sentit, la literatura prèvia es centra principalment en la cost-efectivitat sobre la població de IC en tots els estadiatges, i no existeixen revisions sistemàtiques que resumeixin la cost-efectivitat en la població de IC avançada.

Les dos mesures que s’empren habitualment en la realització de les avaluacions econòmiques són els anys de vida guanyats (AVG) dins els estudis de cost-efectivitat, i d’altra banda els anys de vida ajustats per qualitat (AVAQ) dins els estudis de cost-utilitat. Els AVG fan referència únicament als anys de vida que la persona adquireix pel fet de realitzar un tractament, en canvi el terme AVAQ té en compte la qualitat d'aquests anys de vida i es calcula a partir de l'ajust dels anys de vida guanyats tenint en compte la utilitat que tenen [96] . En economia de la salut, la "utilitat" és la mesura que fa referència al valor que un individu dona a un estat de salut en particular. Generalment va des del 0 (mort) al 1 (salut perfecta) [97].

Cost-efectivitat

Els anàlisis de cost-efectivitat són aquells que permeten discernir si una intervenció té suficient valor com per incloure-la dins d'una determinada cartera de serveis [98].

Una revisió sistemàtica recent que compara diferents intervencions d'infermeria (visites a domicili, gestió de casos liderada per infermeres o visites a una clínica de IC) i la seva **cost-efectivitat**, conclou que qualsevol de les tres intervencions és més costosa que l'atenció habitual dels pacients, però també és més efectiva. En un horitzó temporal de tota la vida, l'atenció a domicili liderada per infermeres, l'atenció basada en visites a una clínica especialitzada i la gestió de casos liderada per infermeres van millorar els anys de vida ajustats per qualitat (AVAQ) respecte l'atenció habitual (2.49, 2.42 i 2.40 AVAQ respectivament vs 2.25 AVAQ). D'altra banda, les intervencions també van augmentar els costos associats fins a 6.629 dòlars en el cas del seguiment a la clínica, o 5.267 dòlars en el cas de la gestió de casos respecte l'atenció habitual (costos de 2018, USD) [99]. Aquesta revisió posa de manifest que cal valorar detalladament la necessitat dels models de gestió de casos, l'efectivitat del mateix i la disponibilitat a pagar del país.

Degut a que no totes les intervencions que tenen efectivitat es poden finançar donada la pròpia limitació dels pressupostos dels països, les agències reguladores inclouen el llindar de cost-efectivitat com a barrera per decidir si es finança una intervenció. Aquest llindar expressa la disponibilitat a pagar de la societat pel guany d'1 AVAQ (el Regne Unit, per exemple, estableix un llindar de 30.000 lliures per AVAQ guanyat) [98]. En el cas d'Espanya, el darrer informe basat en enquestes que recollien les preferències en una mostra amplia i representativa de la societat espanyola, va concloure que el llindar de cost-efectivitat estimat al nostre entorn estava entre 20.000€ i 25.000€ [100].

Cost-benefici

El concepte cost-benefici parla sobre l’estalvi monetari que es pot desenvolupar a conseqüència d’una intervenció. En relació al **cost-benefici** de la GC, es coneix que la reducció potencial en les hospitalitzacions i visites a urgències, podria tenir un paper en la reducció dels costos. En canvi, els estudis publicats fins al moment han mostrat resultats inconsistents amb un baix nivell d’evidència [101].

L’estudi de costos més recent ha estat el realitzar pel grup de Weinstein et al, l’any 2021. Aquest estudi analitza els costos derivats de les hospitalitzacions en població amb IC general dins un programa multidisciplinari a la comunitat i conclou que la cohort de pacients analitzada sota la intervenció, reduïa un 27% els costos d’hospitalizació durant un any de seguiment [102]. La intervenció de l’estudi de Weinstein es va basar en les recomanacions de la societat europea de cardiologia (ESC) de l’any 2021.

Aquesta societat recomana que els pacients amb IC siguin atesos per equips multidisciplinaris a domicili o a la clínica, ja que l’educació del maneig de la malaltia és cabdal per reduir les hospitalitzacions i la mortalitat [1], en canvi, la guia no especifica quins professionals haurien de formar part de l’equip, ni si l’equip hauria d’estar liderat per un professional en concret o des de quina perspectiva es podria fer un millor seguiment del pacient (telemonitoratge, visites a domicili, visites ambulatòries etc). És per això, que es considera rellevant descriure en profunditat les intervencions realitzades en aquests pacients, ja que conèixer quin tipus d’atenció millora els resultats de salut és cabdal per atendre de la manera més òptima a aquesta població.

Degut a la necessitat de conèixer la cost-efectivitat de la intervenció en els pacients amb IC avançada i degut a que no existeixen revisions sistemàtiques analitzant l’evidència sobre aquest impacte, un dels objectius d’aquesta tesi és analitzar el cost i cost-efectivitat de la GC liderada per infermeres en l’entorn de l’atenció primària en pacients amb IC avançada.

3. JUSTIFICACIÓ DEL TREBALL

La insuficiència cardíaca (IC) és una malaltia molt prevalent a nivell mundial i al nostre país amb un deteriorament important en la qualitat de vida de qui la pateix. El procés de la malaltia avança durant el transcurs de la vida de la persona fins instaurar-se la insuficiència cardíaca avançada. La IC avançada té greus repercussions en termes de mobilitat, símptomes, qualitat de vida, descompensacions cardíaques que requereixen hospitalització i clarament un major risc de mortalitat que en estadiatges més inicials. Tot i que existeix molta evidència en referencia a la IC, la IC avançada ha estat menys estudiada.

A l'entorn de l'atenció primària, conèixer quins factors poden predir la mortalitat en el pacient amb IC avançada, és important des del punt de vista terapèutic. Conèixer quines característiques estan relacionades amb un pitjor pronòstic ajuda a dissenyar una atenció orientada al moment que viu la persona. En aquest sentit, es coneix que algunes dades clíniques poden predir la mortalitat, en canvi, els professionals de la salut de l'AP també valoren altra informació relacionada amb l'entorn de la persona mitjançant escales validades (com és el cas del risc social), tot i que fins el moment, no s'ha analitzat quina relació podrien tenir aquestes eines amb la mortalitat dels pacients. Per tant, conèixer si la valoració social del pacient realitzada de manera habitual pot predir la mortalitat seria d'interès a l'hora d'elaborar un pronòstic.

D'altra banda, conèixer com afecta la malaltia al dia a dia i quines estratègies d'afrontament utilitzen els pacients és important per establir una millor relació terapèutica i satisfer millor les necessitats de les persones. Es coneix poca informació sobre la experiència viscuda dels pacients amb IC avançada, i encara menys al nostre entorn. La experiència és quelcom subjectiu i per tant, les dades que s'obtenen en entorns diferents al nostre podrien no ser transferibles als pacients atesos al nostre sistema de salut. Aquesta tesi proposa estudiar en profunditat les experiències del pacients vivint amb IC avançada a l'entorn comunitari. La informació obtinguda serà de gran valor pels professionals de l'atenció primària i per tots aquells que atenguin a persones en la fase final de la malaltia.

Finalment aquest treball es planteja avaluar l'efectivitat del programa de gestió de casos liderat per infermeres a la comunitat en pacients amb IC avançada. És conegut que els programes de gestió de casos liderats per infermeres són un model utilitzat en pacients amb malalties cròniques i concretament amb IC, en canvi, mai s'ha fet una revisió sistemàtica de la literatura sobre l'impacte en termes d'efectivitat (qualitat de vida, ingressos hospitalaris, mortalitat i millora de l'autocura) en pacients amb IC avançada que reben l'atenció per part d'una infermera gestora de casos en l'entorn comunitari.

Degut a que les intervencions s’implementen en base a la cost-efectivitat de les mateixes, aquesta tesi recull una avaluació econòmica de l'impacte de la gestió de casos. Les avaluacions econòmiques són una eina per conèixer els recursos que són imprescindibles per implementar una intervenció, i d’altra banda, ajuden en l’elecció de les intervencions a implementar tenint en compte els beneficis que aporten en base al pressupost de cada país. Per tant, les avaluacions econòmiques tenen una gran rellevància a nivell social i sanitari.

Hi ha escassa informació sobre la cost-efectivitat de la intervenció en el subgrup de població amb IC avançada i no és clarament sòlida a favor de la intervenció. Es considera rellevant la síntesis de la informació mitjançant una revisió exhaustiva dels estudis publicats ja que aquests resultats, obririen nou coneixement que ajudaria a la presa de decisions en la implementació de programes.

Els resultats d’aquesta tesi pretenen, per una banda conèixer determinants pronòstics de mortalitat relacionats amb la valoració habitual del risc social al domicili, explorar com viuen les persones el procés final de vida de la IC avançada, i analitzar l’efectivitat i la cost-efectivitat de la gestió de casos liderada per infermeria a l’entorn de l’atenció primària de salut. Els resultats obtinguts permeten entendre millor el procés de final de vida, millorar l’atenció segons les necessitats expressades i aportar coneixements d’efectivitat i cost-efectivitat d’un model d’atenció per tal de prendre decisions en salut.

4. HIPÒTESIS

1) El context social de les persones amb insuficiència cardíaca avançada influeix en el seu pronòstic de mortalitat.

2) Per respondre les vivències dels pacients amb IC avançada s'ha fet un enfocament qualitatiu, per la qual cosa enlloc de partir d’una hipòtesi s'ha fet des d’una pregunta d’investigació: Com és l'experiència viscuda de les persones que pateixen insuficiència cardíaca avançada a l’entorn de l’atenció primària de salut?

3) El model de gestió de casos liderat per infermeres en persones amb IC avançada redueix la mortalitat i les hospitalitzacions, i d’altra banda, millora la qualitat de vida i l’adherència al tractament.

a) El model de gestió de casos liderat per infermeres és un model clínic cost-efectiu.

5. OBJECTIUS

5.1 OBJECTIU GENERAL

Explorar l’impacte del context social i l’experiència de les persones insuficiència cardíaca avançada i avaluar l’efecte i l’efectivitat d’un model de gestió clínica en la fase avançada de la malaltia.

5.2 OBJECTIUS ESPECÍFICS

1) Avaluar l’impacte del context social de les persones en la mortalitat de la insuficiència cardíaca avançada.

2) Explorar, des de la perspectiva fenomenològica i holística, l’experiència dels pacients que viuen amb insuficiència cardíaca avançada, atesos a domicili en l’entorn de l’atenció primària l’any 2018.

3) Revisió de l'evidència de l’efectivitat, cost i cost-efectivitat de la intervenció de la infermera gestora de casos en pacients amb IC avançada en la mortalitat, hospitalitzacions per totes les causes, hospitalitzacions per IC, qualitat de vida i adherència al tractament.

6. MÈTODES

Aquesta tesi es presenta per compendi de publicacions, i per tant, els mètodes en aquesta secció corresponen a cadascun dels tres articles publicats. Per respondre cada objectiu s'ha utilitzat la metodologia que millor responia a la pregunta d'investigació. De manera que en aquest treball s'ha utilitzat la perspectiva quantitativa, qualitativa i la revisió sistemàtica. En aquest apartat es troba un resum dels diferents tipus d'estudi, poblacions d'estudi, mètodes de recollida i anàlisi de les dades.

6.1 RESUM DEL MATERIAL I MÈTODES DE CADA ARTICLE

Objectiu 1: Avaluar l'impacte del context social de les persones en la mortalitat de la insuficiència cardíaca avançada.

Article 1.

"Social Risk and mortality: a cohort study in patients with Advanced heart failure".

Títol	Social Risk and mortality: a cohort study in patients with Advanced heart failure
Autors	C. Checa, R. Abellana, JM. Verdú-Rotellar, A. Berenguera, M. Domingo, E. Calero, MA. Muñoz-Pérez
Referència	Journal of Cardiovascular Nursing. 34(1):E8-E15. doi: 10.1097/JCN.0000000000000538.
Revista	Journal of Cardiovascular Nursing
Any	2019
Paraules Clau	Heart failure, mortality, primary care, social determinants of health, social support
Índex de citació	*Science Citation Index*
Factor d'impacte	2.083

Categoria	Nursing
Quartil en la categoria	Q2
Posició en la categoria	42/123

DISENY

Estudi analític de cohorts retrospectives.

POBLACIÓ D'ESTUDI

La població d'aquest estudi està formada per tots els pacients de Catalunya majors de 45 anys diagnosticats amb IC a la història clínica segons la Classificació Internacional de malalties, amb el codi: ICD-10 I 50 i en l'estadi IV de la NYHA entre l'1 de gener del 2010 i el 31 de desembre del 2013.

A causa del gran nombre de pacients analitzats en aquest estudi (n=1.148), que comprèn gairebé totes les persones en la classe NYHA IV de la nostra població a Catalunya, no es va realitzar un càlcul de mostra i els resultats obtinguts tenen la capacitat de respondre l'objectiu de l'estudi.

FONTS D'INFORMACIÓ

Les dades es van recollir sobre el registre del Sistema d'Informació per al Desenvolupament de la Investigació en Atenció Primària (SIDIAP) [103]. Aquesta base de dades conté les dades clíniques i estat de salut de 5,215.912 habitants atesos a 274 centres d'atenció primària situats arreu del territori català. Cada ciutadà té un codi d'identificació personal únic vinculat a l'administració sanitària i es manté anònim per als propòsits d'aquest estudi.

Es van recollir les dades relacionades amb l'autocura, estat clínic, funcionalitat i risc social que es detallen a continuació i es va estudiar si tenien relació amb la mortalitat de les persones:

Edat
Gènere
Pressió arterial sistòlica
Freqüència cardíaca

Índex de massa corporal
Índex de comorbiditat de Charlson i comorbilitats associades (hipertensió, diabetis, malalties del cor, ictus, insuficiència renal, malaltia pulmonar obstructiva crònica, fibril·lació auricular i càncer),
Índex Barthel
Escala Sòcio-Familiar de Gijón

ANÀLISI

Per a la descripció de les variables descriptives contínues es van resumir mitjançant la mitjana i la desviació estàndard i les variables categòriques es van mostrar en números absoluts i percentatges.

La mortalitat per totes les causes es va analitzar en relació al risc social mitjançant l’Escala d’Avaluació Socio-familiar de Gijón i per analitzar la supervivència de les persones vers aquest risc es va representar mitjançant la corbs de Kaplan-Meier.

D’altra banda també es va analitzar l’efecte de les característiques del pacients en termes demogràfics, comorbiditats i variables clíniques en la supervivència. Per avaluar això es va fer servir el model de Cox i el nivell de significació estadística es va fixar en .05.

Tot l’anàlisi es va realitzar amb el programari R per a Windows versió 3.3.2 (R Project per a la informàtica estadística; Viena, Àustria).

ASPECTES ÈTICS

El protocol d'estudi va ser aprovat per Primària Institut Universitari de Recerca Sanitària IDIAP-Jordi Gol (codi: P15/065). Es va garantir la confidencialitat dels pacients, i la investigació s'ajustava als principis de la Declaració de Hèlsinki [104].

Objectiu 2: Explorar, des de la perspectiva fenomenològica i holística, l'experiència dels pacients que viuen amb insuficiència cardíaca avançada, atesos a domicili en l'entorn de l'atenció primària l'any 2018.

Article 2. **"Living with advanced heart failure: a qualitative study".**

Títol	Living with advanced heart failure: a qualitative study
Autors	C. Checa, L. Medina-Perucha, MA. Muñoz, JM. Verdú-Rotellar, A. Berenguera
Referència	PLoS ONE 15(12): e0243974. https://doi.org/10.1371/journal.pone.0243974
Revista	Plos One
Any	2020
Paraules Clau	Qualitative research, advanced heart failure, primary care, patients' experiences.
Índex de citació	*Science Citation Index*
Factor d'impacte	3.240 (2020)
Categoria	Multidisciplinary sciences
Quartil en la categoria	Q2
Posició en la categoria	26/72

OBJECTIU PRINCIPAL

Explorar, des de la perspectiva fenomenològica i holística, l'experiència dels pacients que viuen amb insuficiència cardíaca avançada, atesos a domicili en l'entorn de l'atenció primària l'any 2018.

DISSENY

Estudi qualitatiu fenomenològic. La corrent fenomenològica utilitzada va ser la de Husserl ja que el que es pretén és conèixer l'experiència de les persones lliure de prejudicis [105].

POBLACIÓ D'ESTUDI

Pacients amb insuficiència cardíaca avançada assignats als centres d'atenció primària (CAP): CAP Roger de Flor, CAP Sant Martí, CAP Clot i CAP Sant Elies.

Per tal d'obtenir varietat i riquesa en el discurs, es va proposar un mostreig tenint en compte certes característiques dels participants: gènere, edat i estat socioeconòmic. A més, es van recollir variables relacionades amb la malaltia: NYHA, número de convivents a la llar, grau de parentiu i cuidador principal.

Els criteris d'inclusió i exclusió s'exposen a continuació:

Criteris d'inclusió	**Criteris d'exclusió**
Pacients diagnosticats amb IC NYHA III i al menys un ingrés hospitalari als darrers sis mesos, o NYHA IV	Demència
Atesos a domicili per professionals d'atenció primària	Discapacitat intel·lectual
Edat > 65 anys	Patologia psiquiàtrica severa
	Presència de símptomes que impedeixin el relat de la vivència

Els pacient que acomplien criteris d'inclusió van ser informats i van signar el consentiment que s'exposa en la secció d'Annexes d'aquesta tesi. La saturació de les dades es va obtenir després de 12 entrevistes en profunditat.

FONTS D’INFORMACIÓ

Les dades d’aquest estudi van ser recollides mitjançant entrevistes en profunditat al domicili dels participants amb la finalitat de recollir les dades en el propi entorn del pacient buscant la seva comoditat i obertura durant l’entrevista. L’entrevistadora va fer preguntes obertes adaptades al llenguatge dels pacients mitjançant una guia de temes que incloïen:

Informació de la malaltia
Relació amb els professionals de la salut
Vida diària
Suport social
Emocions
Futur

Els participants tenien l'oportunitat de parlar de temes no inclosos a la guia i que consideressin rellevants. Les entrevistes van ser gravades, transcrites i contextualitzades amb notes de camp fetes per la mateixa entrevistadora.

ANÀLISI DE LES DADES

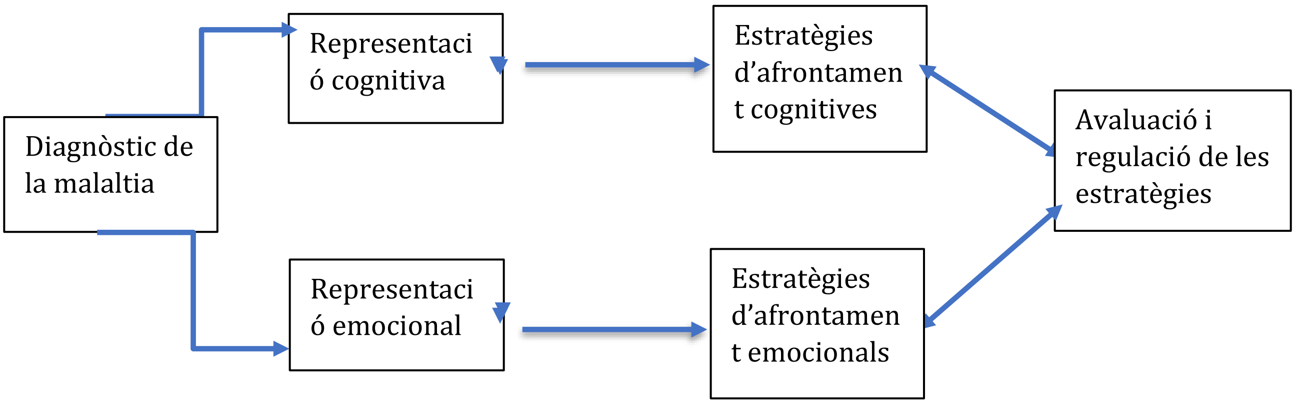
Per analitzar les entrevistes es va utilitzar l'anàlisi de contingut temàtic emprant les passes desenvolupades per Berenguera et al [106]. En primer lloc, es van llegir i rellegir les entrevistes per aconseguir una pre-analítica. A continuació, es van analitzar les dades a partir de les següents passes: a) identificació dels temes principals, b) fragmentació en unitats de significat, c) codificació de textos amb estratègia mixta (es va utilitzar el marc teòric de Leventhal [107] i codis emergents), d) creació de les categories, e) anàlisi de cada categoria i f) elaboració de resultats. Tots els membres de l’equip van participar en l’anàlisi de dades posicionant-se des de la reducció fenomenològica fins a arribar a un consens (triangulació de les dades).

Marc teòric de Leventhal

El marc teòric emprat per l’anàlisi de les dades va ser el de Leventhal [107], aquest considera a les persones com a membres actius dels seus problemes de salut.

Quan una persona rep un diagnòstic, aquest es percep com una amenaça a la vida d’un mateix, i com a resposta, es desenvolupen representacions emocionals i cognitives. Un cop apareixen aquestes, els individus utilitzen estratègies d’afrontament per fer front a les representacions viscudes. Aquestes estratègies seran avaluades i es regularà la resposta en un sistema continu de retroalimentació (Figura 2).

Figura 2: Marc teòric de Leventhal



ASPECTES ÈTICS

L'estudi va seguir els principis de la Declaració d'Hèlsinki i la bona pràctica d'investigació clínica [104]. Tots els participants van signar un formulari de consentiment informat per escrit abans d'iniciar les entrevistes i que s'exposa en l'apartat Annexes de la present tesi. La confidencialitat i l'anonimat es va garantir assignant a cada participant un codi que s'utilitzava per identificar-lo a les transcripcions. El projecte va ser aprovat pel Comitè d'Ètica i Recerca Clínica de l'Institut d'Investigació d'Atenció Primària Jordi Gol (4R17/010). Les gravacions d'àudio seran eliminades de forma segura després de 5 anys de la finalització de l'estudi.

Objectiu 3: Revisió de l'evidencia de l'efectivitat, cost i cost-efectivitat de la intervenció de la infermera gestora de casos en pacients amb IC avançada en la mortalitat, hospitalitzacions per totes les causes, hospitalitzacions per IC, qualitat de vida i adherència al tractament.

Article 3.

“Effectiveness and cost-effectiveness of case management in advanced heart failure patients attended in primary care: a systematic review and meta-analysis.”

Títol	Effectiveness and cost-effectiveness of case management in advanced heart failure patients attended in primary care: a systematic review and meta-analysis
Autors	C. Checa, Canelo-Aybar C, Suclupe S, Ginesta-López D, Berenguera A, Castells X, Brotons C, Posso M
Referència	*Int. J. Environ. Res. Public Health* **2022**, *19*(21), 13823; **https://doi.org/10.3390/ijerph192113823**
Revista	International Journal of Environmental Research and Public Health
Any	2022
Paraules Clau	case management, advanced heart failure, cost-effectiveness, meta-analyses, mortality, quality of life, hospital admissions, self-care
Índex de citació	*Science Citation Index*
Factor d’impacte	4.614 (2021)
Categoria	Public, environmental & occupational health
Quartil en la categoria	Q2
Posició en la categoria	71/210

DISSENY

Revisió sistemàtica i metaanàlisi.

ESTUDIS INCLOSOS A LA REVISIÓ I METAANÀLISI

Es van incloure els estudis descrits com assajos clínics, estudis quasi-experimentals, i estudis de cohorts amb un grup control.

A continuació s'exposa els criteris dels participants, intervencions, grup control i resultats inclosos en aquesta revisió.

Població d'estudi	Estudis amb pacients majors de 18 anys amb IC avançada definida com a estadiatge III o IV de la NYHA o estadi D de la American College of Cardiology Foundation/American Heart Association (ACCF/AHA), o pacients en tractament pal·liatiu.
Intervenció	Estudis on s'avalués l'impacte de la gestió de casos liderat per infermeres a la comunitat. El model de GC podria ser multidisciplinari però la infermera hauria de tenir un major pes en el seguiment i educació sanitària del pacient.
Grup control	Estudis que comparessin la intervenció amb l'atenció habitual o un altre programa de gestió de casos a la comunitat.
Objectiu principal	Estudis on s'avalués l'efecte del programa de gestió de casos liderada per infermeres en la mortalitat dels pacients amb IC avançada a l'entorn comunitari.
Objectius secundaris	Estudis que mesuressin l'efecte del programa de GC en relació a la qualitat de vida, hospitalitzacions, adherència al tractament,

	efectes no desitjats, costos i cost-efectivitat del programa.

FONTS D'INFORMACIÓ

Es va fer una cerca a les bases bibliogràfiques: MEDLINE, CINAHL, Embase, Clinical Trials, WHO, Registry of International Clinical Trials i Central Cochrane. Els estudis en curs es van identificar mitjançant la web US ClinicalTrials.gov (https://ClinicalTrials.gov/), la plataforma World Health Organization International Clinical Trials Registry (ICTRP) (http: // apps .who.int / trialsearch /) i el registre ISRCTN (https://www.isrctn.com/).

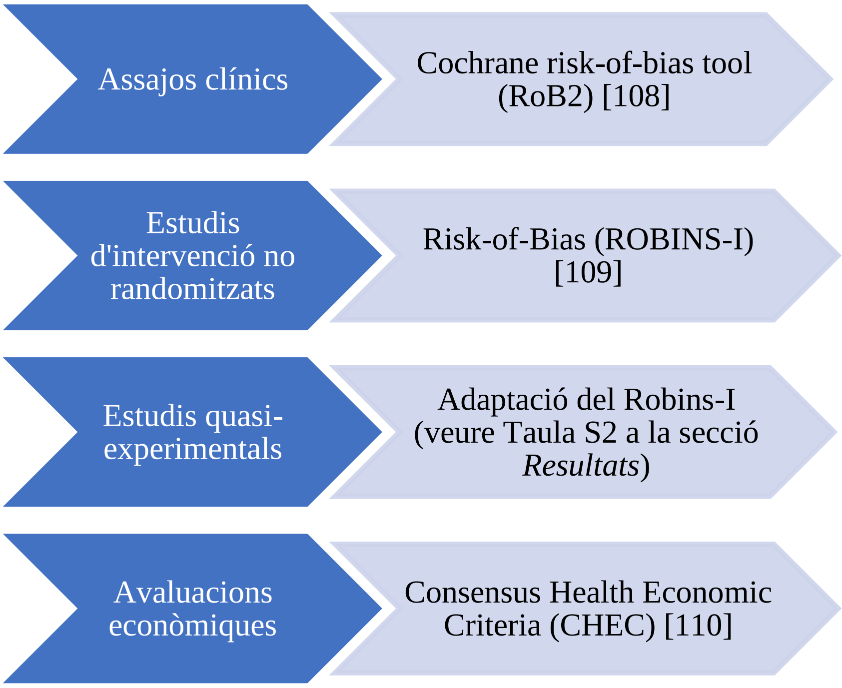
No es van fer restriccions per any de publicació i es van incloure estudis en anglès, castellà i francès fins el març de 2022.

ANÀLISI DE LES DADES

Per analitzar les dades dels estudis extrets de la cerca bibliogràfica es van recollir les dades següents de manera descriptiva: autor/s, any de publicació, disseny de l'estudi, característiques de la mostra, característiques de la intervenció (seguiment del pacient, tipus d'educació sanitària realitzada i durada de la intervenció), i resultats analitzats a l'estudi (qualitat de vida i/o mortalitat i/o hospitalització i/o autocura i/o costos o cost-efectivitat i/o efectes indesitjables). També es va recopilar informació sobre finançament econòmic dels estudis.

Per analitzar el risc de biaix en els estudis inclosos es van fer servir les següents eines (Figura 3):

Figura 3: Eines utilitzades per l’avaluació de risc de biaix segons el disseny de l’estudi.



Per representar els estudis escollits es van resumir les característiques descriptives en taules i l’anàlisi de dades es va realitzar segons l’enfocament d'intenció de tractar incloent tots els participants per reduir el possible biaix de selecció.

Es van analitzar les dades dels objectius secundaris de qualitat de vida, mortalitat, hospitalització, adherència al tractament, costos, rendibilitat i efectes indesitjables durant els següents períodes de seguiment: < 6 mesos, 6-12 mesos i > 12 mesos.

Les dades adequades per agrupar-se en un metaanàlisi es van agrupar i meta-analitzar mitjançant Review Manager (RevMan, versió 5.3.5., Cochrane Collaboration, Oxford, Regne Unit) i el programari STATA (v.14.0, STATA Corp).

Es va jutjar la magnitud de l'heterogeneïtat entre els estudis primaris inclosos mitjançant les estadístiques I^2 de Higgins que es van interpretar segons les directrius del Manual Cochrane (*del 0% al 40%: baix*, del *30% al 60%: moderat*, del *50% al 90%: substancial*, *75% a 100%: considerable*). A més, es van inspeccionar visualment els diagrames d’efectes (*forest plot*) dels metaanàlisi atès que les estadístiques I^2 es podrien inflar artificialment quan les estimacions dels efectes dels estudis primaris eren molt precises [111].

ASPECTES ÈTICS

El protocol d’aquest estudi es va registrar prèviament a l’inici de la revisió al Registre Prospectiu Internacional de Revisions Sistemàtiques (PROSPERO) i es va publicar amb el número d'identificació CRD42020160810 l'any 2020. El protocol inclou la revisió, l'estratègia de cerca, els criteris d'inclusió/exclusió i l'avaluació del risc de biaix.

7. RESULTATS

Els resultats d'aquest apartat corresponen als diferents estudis desenvolupats que han donat lloc a la publicació de tres articles i que s'exposen a continuació:

Article 1: Checa C, Abellana R, Verdú-Rotellar JM, Berenguera A, Domingo M, Calero E, Muñoz Pérez MA. Social Risk and Mortality: A Cohort Study in Patients With Advanced Heart Failure. J Cardiovasc Nurs. 2019;34(1):E8-E15. doi: 10.1097/JCN.0000000000000538.

Article 2: Checa C, Medina-Perucha L, Muñoz MÁ, Verdú-Rotellar JM, Berenguera A. Living with advanced heart failure: A qualitative study. PLoS One. 2020;15(12):e0243974. doi: 10.1371/journal.pone.0243974.

Article 3: Checa C, Canelo-Aybar C, Suclupe S, Ginesta-López D, Berenguera A, Castells X, Brotons C, Posso M. Effectiveness and Cost-Effectiveness of Case Management in Advanced Heart Failure Patients Attended in Primary Care: A Systematic Review and Meta-Analysis. Int J Environ Res Public Health. 2022;19(21):13823. doi: 10.3390/ijerph192113823.

Journal of Cardiovascular Nursing
Vol. 34, No. 1, pp. E8–E15 | Copyright © 2019 Wolters Kluwer Health, Inc. All rights reserved.

Social Risk and Mortality

A Cohort Study in Patients With Advanced Heart Failure

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Background: Heart failure (HF) is a chronic condition that usually leads to death a few years after diagnosis. Although several clinical factors have been found to be related to increased mortality, less is known about the impact of social context, especially at the end stage of the disease. Knowing about social context is important to properly classify risk and provide holistic management for patients with advanced HF. **Objective:** The aim of this study was to determine the impact of social context on mortality in patients with advanced HF. **Methods:** A retrospective cohort study was conducted using data from clinical records on community-dwelling patients with HF and with New York Heart Association IV functional class living in Catalonia in northeastern Spain. Clinical data, patient dependency for basic activities of daily living, and social assessments were collected between 2010 and 2013. The primary outcome was all-cause mortality. **Results:** Data from 1148 New York Heart Association class IV patients were analyzed. Mean (SD) age was 82 (9.0) years, and 61.7% were women. The mean (SD) follow-up was 18.2 (11.9) months. Mortality occurred in 592 patients. Social risk was identified in 63.6% of the patients, and 9.3% acknowledged having social problems. In the adjusted multivariate model, being male (hazard ratio (HR), 1.82; 95% confidence interval [CI], 1.16–2.83), having high dependency on others for basic activities of daily living (HR, 2.16; 95% CI, 1.21–3.85), and presenting with a social problem (HR, 2.46; 95% CI, 1.22–4.97) were related to an increased risk of mortality. **Conclusions:** An unfavorable social profile is an independent risk factor for mortality in patients with advanced HF.

KEY WORDS: heart failure, mortality, primary care, social determinants of health, social support

Heart failure (HF) is a chronic and progressive condition that involves episodes of decompensation leading to hospitalization and death in a high proportion of patients a few years after onset.[1] In the United States, it is estimated that HF affects up to 5.7 million American adults,[2] whereas a recent European study showed a mortality rate greater than 17% after an acute episode.[3,4]

Advanced HF is defined by the presence of cardiac failure symptoms at rest, or during minimal effort, despite optimal treatment.[5] Most studies consider advanced HF as corresponding to classes III to IV of the New

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The authors have no funding or conflicts of interest to disclose.

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DOI: 10.1097/JCN.0000000000000538

York Heart Association (NYHA) scale,[6] with patients at stage IV the most physically dependent.[7] A holistic approach, including functional status and social assessment, is needed, especially at the final stage of the disease, because such aspects could influence quality of life and even prognosis.[8]

Although classical risk factors (hypertension, diabetes, smoking, and dyslipidemia) have been used to predict the progress of cardiovascular diseases,[9] almost 25% of fatal cases are not completely explained by such aspects and other determinants are clearly operational.[10] The circumstances and conditions in which individuals reside, learn, and work, as well as the affection they receive from others, have been described as having an impact on health.[11]

The study of social determinants includes several components such as education, place of birth, migration, neighborhood, housing and working conditions, economic position, and environment.[12] The accumulation of unfavorable social determinants may lead to a situation of social risk; nevertheless, there is some controversy about the usefulness of such factors when assessing patients. Keyhani et al[13] designed a model to predict the risk of stroke readmission considering some measures of social risk. The items, however, were considered separately and did not improve performance of the predictive model. Another study showed that both social support perception and economic status were related to a worse quality of life and higher mortality in patients with HF.[14] In a systematic review of patients with HF, it was demonstrated that poor housing conditions, such as not having an elevator or a heater, were associated with increased mortality.[15]

In Catalonia, a region of northeastern Spain, the National Health System has implemented a program to follow up patients with HF, which is mainly conducted by nurses.[16] This program includes the evaluation of environmental and social situation and assesses social risk in patients seen in the community, by analyzing family situation, housing conditions, economic status, social relationships, and social support.[17]

Because the assessment of social risk factors remains controversial and evidence from comprehensive models is scarce, we aim to determine the impact of social risk on mortality in patients with advanced HF seen in primary care.

Material and Methods

Design and Setting

A retrospective cohort study was conducted between January 1, 2010, and December 31, 2013. Participants were community-dwelling patients with NYHA class IV HF, 45 years or older. The inclusion date was defined by the moment patients were registered as NYHA class IV in their clinical records.

Variables, Measures, and Sources of Information

Data were collected as established in the regional HF follow-up program. All patients were assessed on self-care, clinical status, functionality, and social risk. Because patients included in this study were all in NYHA class IV, data were collected by community nurses in the patients' homes. The information collected was systematically entered into the electronic medical record, which was stored in a centralized database called Information System for the Enhancement of Research in Primary Care. This database contains the clinical data and vital status of patients seen at the 274 primary healthcare centers located throughout the Catalan territory,[18] which belongs to the Catalan Institute of Health covering 5 215 912 inhabitants (70% of the population). Every citizen has a unique personal identification code linked to the healthcare administration, which was centralized and kept anonymous for the purposes of this study.

Independent Variables

Independent variables considered in the analysis were sociodemographic information (gender and age), systolic blood pressure, heart rate, body mass index, comorbidity (hypertension, diabetes, heart disease, stroke, renal impairment, chronic obstructive pulmonary disease, atrial fibrillation, and cancer), Charlson Comorbidity Index, Barthel Index, and Gijón Social-Familial Evaluation Scale. The Charlson Index considers comorbidity to be elevated if the score is greater than 5, and the Barthel Index indicates high dependency if scores are less than 20.[19–21]

The Gijón Social-Familial Evaluation Scale was the main independent variable and was used to assess social risk. The instrument has been validated in Spain and shown to have a high concordance among the different items. The interobserver concordance of the original scale was 0.96, and the concordance among the different items had κ indices between 0.80 and 0.93.[22] The Social-Familial Evaluation Scale was developed and validated to measure various social aspects and is divided into 5 domains: family context, economic status, housing conditions, social relationships, and social networks. Every item is scored from 1 to 5, with higher scores indicating a higher social risk. The final score is classified into 3 categories: good social situation (<10 points), social risk (10–16 points), and social problem (>16 points). The Social-Familial Evaluation Scale information was obtained by primary care nurses who personally interviewed patients.

Family assessment included whether the patient lived alone and, if the patient lived with someone else, whether this person had any kind of dependency.

Economic status measured the patient's income, which was classified into 5 different ranges: (1) more than 1.5 fold the national minimum salary (NMS) (>16 $701.90 dollars per year), (2) from the NMS to 1.5 fold the NMS (from $11 134.60 to $16 701.90 dollars per year), (3) from the NMS to the minimum pension (from $10 332.20 to $11 134.60 dollars per year), (4) individuals receiving a benefit pension from the government (from $6 296.30 to $10 332.20 dollars per year), and (5) those with very low or no income (<6 $296.30 dollars per year).

To assess housing conditions, factors such as structural barriers, squalor, and humidity were evaluated. Social relationships were measured by asking whether the patient had relationships with their relatives and/or neighbors.

Finally, social networks evaluated the informal and formal support that the patient received. These data were categorized as family and neighbors, informal support, no support, waiting list for a nursing home, or need for permanent care.

The *International Classification of Diseases, Tenth Revision*, was used to codify the HF diagnoses (ICD-10 I 50). The outcome variable of this study was total mortality occurring during follow-up, which was obtained from the administrative Central Registration Patient Database.

Dependent Variable

The outcome of focus was all-cause mortality for patients with NYHA class IV HF. We used all-cause rather than HF-related mortality because, especially in patients with preserved ejection fraction, hospitalization and mortality are due to comorbid, noncardiovascular causes.

Sample Size

Because of the large number of patients analyzed in this study, which comprises almost the entire NYHA class IV population seen in our region, our results have statistical power to address the objectives of the study.

Ethical Considerations

The study protocol was approved by the Primary Health Care University Research Institute IDIAP-Jordi Gol (P15/065). The confidentiality of patients was guaranteed, and the investigation conformed to the principles outlined in the Declaration of Helsinki.[23]

Statistical Analyses

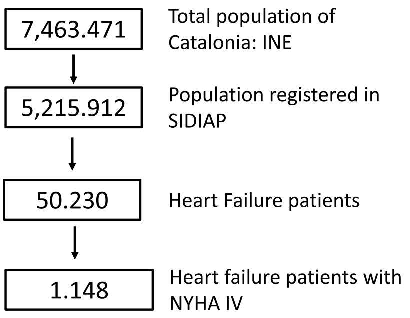
Continuous variables were summarized using mean and standard deviation, and categorical variables were analyzed with total number and percentages. The mortality density rate was calculated for the Social-Familial Evaluation Scale items. Event-free survival was evaluated with the Kaplan-Meier method. The effect of patient characteristics (demographics, comorbidities, clinical and dependency issues, and social assessment) on survival was investigated using the Cox proportional hazards model. Variables with a statistically significant effect on survival in the univariate analyses were entered in a multivariate Cox proportional hazards model. A multiple imputation method was used to deal with the missing values of variables considered in the multivariate model. To carry out the imputations, patient data regarding survival status and event-free time were taken into account. Twenty data sets were performed, and the values were combined using Rubin's rules. Significance level was fixed at .05. Analysis was conducted with R software for Windows version 3.3.2 (R Project for Statistical Computing; Vienna, Austria).

Results

A total of 1148 patients with HF (NYHA class IV) were analyzed (Figure 1). Mean (SD) age was 82 (9.0) years, and 61.7% were women. Mean (SD) follow-up was 18.2 (11.9) months, and mortality occurred in 592 patients during this period. Figure 2 shows the survival and cumulative incidence of mortality during the study period. The highest mortality occurred during the first 2 years of follow-up (51%), with an incidence of 36.4 per 100 patients a year.

Almost 80% of the patients were hypertensive, 35% had renal impairment, and 20% had cancer. Few had systolic blood pressure of 90 mm Hg or lower, low body mass index (<20 kg/m^2), or a high level of comorbidity (Charlson Index > 5). More than 10% of the patients had a high dependency in basic ADL (Barthel Index < 20). Regarding social assessment, most (63.6%) had social risk, and about 10% could be classified as having a social problem.

With respect to mortality risk factors, being a woman was protective. However, being older and having renal impairment, cancer, hypotension, a low body mass index, and a high level of comorbidity were related to higher mortality. In addition, a high dependency in basic ADL and scoring "social problem" on the risk scale



INE: Spanish National Institute of Statistics
SIDIAP: Information System for eh Enhancement of Research in Primary Care
NYHA: New York Heart Association

FIGURE 1. *Selection of participants.*

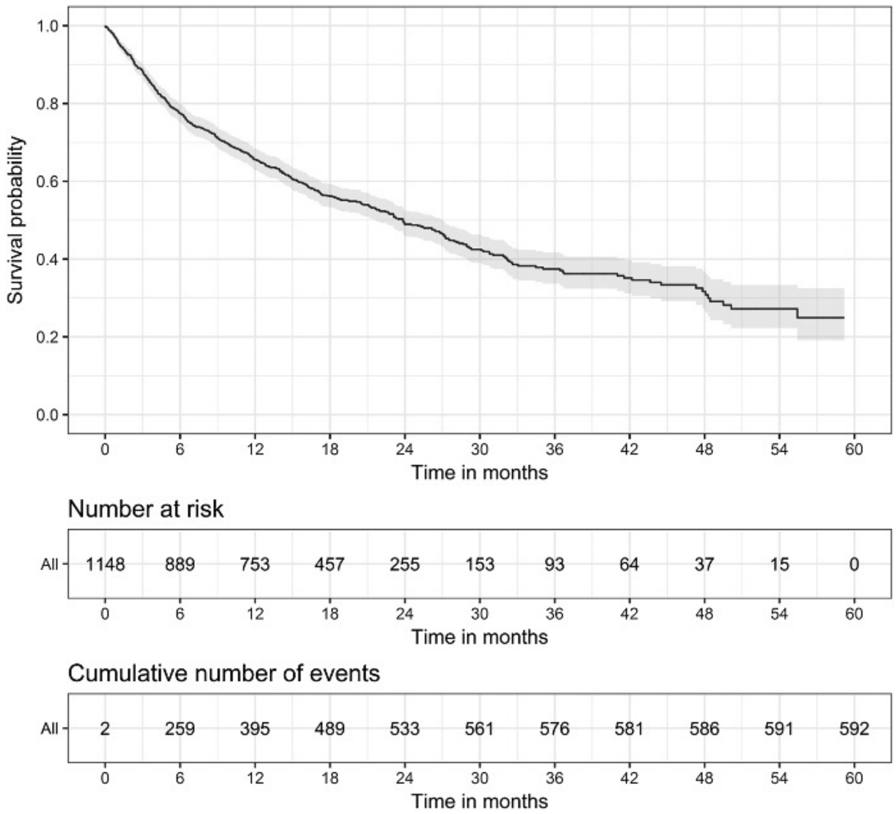


FIGURE 2. *Survival and cumulative incidence of mortality in patients with advanced heart failure.*

TABLE 1 **Baseline Characteristics of Patients With Advanced Heart Failure and Variables Associated With Mortality**

	Total		Deceased		Alive				
	Mean	**SD**	**Mean**	**SD**	**Mean**	**SD**	***P***	**HR**	**95% Confidence Interval**
Age, y	82.0	9.0	83.4	7.9	79.7	9.3	<.001	1.04	1.03–1.05
	n	**%**	**n**	**%**	**n**	**%**			
Gender (male)	440	38.3	255	43.1	185	33.3	<.001	1.39	1.18–1.64
Comorbidity									
Hypertension	909	79.2	460	77.7	449	80.8	.212	1.13	0.73–1.07
Diabetes	485	42.2	251	42.4	234	42.1	.961	1.00	0.85–1.18
Coronary heart disease	375	32.7	197	33.3	178	32.0	.771	0.97	0.82–1.16
Stroke	164	14.3	86	14.5	78	14.0	.770	1.03	0.82–1.30
Kidney impairment	391	34.1	229	38.7	162	29.1	<.001	1.38	1.17–1.63
Chronic obstructive pulmonary disease	378	32.9	208	35.1	170	30.6	.085	1.16	0.98–1.37
Atrial fibrillation	536	46.7	282	47.6	254	45.7	.717	1.03	0.88–1.21
Cancer	216	18.8	135	22.8	81	14.6	<.001	1.58	1.30–1.91
Clinical data									
Systolic blood pressure ≤ 90 mm Hg	37	3.5	27	4.9	10	1.9	.002	1.85	1.26–2.72
Heart rate > 100 beats/min	55	5.4	23	4.5	32	6.4	.632	0.90	0.59–1.37
Body mass index ≤ 20 kg/m^2	36	4.2	25	5.9	11	2.6	<.001	2.51	1.67–3.77
Charlson Index > 5	155	13.5	101	17.1	54	9.7	<.001	1.56	1.26–1.93
Barthel index ≤ 20	90	12.3	64	14.8	26	8.6	<.001	1.64	1.25–2.14
Social assessment									
Good	44	27.2	25	26.6	19	27.9	.040		
Social risk	103	63.6	56	59.6	47	69.1		0.94	0.59–1.50
Social problem	15	9.3	13	13.8	2	2.9		2.01	1.03–3.93

Abbreviation: HR, hazard ratio.

were also linked to a greater risk of mortality. More than 85% of the patients with a social problem died during the follow-up, and mortality in this group was statistically higher than those with a social risk or a good social situation (Table 1).

Considering the items of the social risk assessment index, the most frequent family situation was living with a relative who was physically dependent. The most common economic status was low (8383.2–9034.2 Euros/year). Housing conditions were considered appropriate in more than 60% of cases. With respect to social relationships, 30% of the patients reported not going out to meet other people, and among those, very few (3.1%) did not receive any kind of visit at home. Social support came mainly from family and neighbors and, in 1 of 5 cases, from volunteers (Table 2).

The probability of survival for longer than 1 year was 0.61 for patients with good evaluation on the Social-Familial Evaluation Scale, 0.66 for those with social risk, but only 0.40 for those with a social problem (Figure 3).

The multivariate analysis demonstrated that men and patients with a high dependency in basic ADL had a greater mortality risk. Patients reporting a social problem had more than a 2-fold risk of dying compared with those with a good social evaluation or only social risk (Figure 4).

Discussion

Patients with advanced HF presenting with social problems confirmed with measurement by a comprehensive scale had an increased risk of mortality. Other variables related to mortality were being male and having a high dependency in basic ADL.

Prevalence of social risk in our population was slightly higher than that obtained by Tobella et al[24] in another study performed in our geographical area with a community-dwelling population and using the Social-Familial Evaluation Scale. These differences may be explained by the high comorbidity and illness severity of our patients at the final stage of HF. In addition, we had a greater proportion of participants with a high dependency in basic ADL. In our study, the common participant profile was that of a patient living alone or with physically dependent relatives, with a low income, acceptable housing conditions, and good social relationships and social networks.

Socioeconomic status is a powerful independent predictor of adverse outcomes in patients with HF. Nevertheless, Hawkins et al[25] could not properly explain the mechanisms and pointed out that other potential social factors could be involved in this excess risk. In their first studies, Marmot et al[26] clearly established the relationship between socioeconomic status and mortality. Various measures have been used to assess the former, including type of employment, income, and educational level.[25,27] In our study, however, there were practically no differences in mortality with respect to income despite that a large proportion of patients (40.1%) had a low income. It is possible that a universal, national health system such as that which exists in Spain may minimize the effect of economic differences.

TABLE 2 Description and Mortality Incidence of the Different Domains of Social Assessment of the Gijón Social-Familial Evaluation Scale

	Patients, n (%)	Mortality Incidence, %
Family context		
Living with relatives (physically independent)	39 (24.1)	4.4
Living with a partner (similar age)	29 (17.9)	3.0
Living with relatives (physically dependent)	58 (35.8)	4.3
Living alone (offspring close to their home)	27 (16.7)	2.6
Living alone (offspring far from their home)	9 (5.6)	4.3
Economic status		
>1.5 fold the NMS (>16 $701.90 dollars/y)	29 (17.9)	3.8
From NMS to 1.5 fold the NMS (from $11 134.60 to $16 701.90 dollars/y)	58 (35.8)	3.8
From $10 332.20 to $11 134.60 dollars/y[a]	65 (40.1)	3.7
From $6 296.30 to $10 332.20 dollars/y[b]	7 (4.3)	3.9
<6 $296.30 dollars/y	3 (1.9)	3.1
Housing conditions		
Appropriate conditions	102 (63.0)	3.2
Structural barriers	54 (33.3)	4.5
Humidity or incomplete facilities, squalor	2 (1.2)	7.0
No elevator or telephone	4 (2.5)	53.2
Living in slum conditions	0 (0.0)	
Social relationships		
Having social relationships (in general)	22 (13.6)	5.1
Having social relationships limited to both relatives and neighbors	49 (30.2)	2.9
Having social relationships limited to relatives or neighbors	41 (25.3)	3.5
Do not leave home but receive visits	45 (27.8)	4.5
Do not leave home and do not receive visits	5 (3.1)	4.9
Social networks		
Family or neighbor support	103 (63.6)	3.4
Volunteer or other support	32 (19.8)	3.6
No support	8 (4.9)	3.6
Waiting list for a nursing home	2 (1.2)	100.0
Need of permanent care	17 (10.5)	6.4

Abbreviation: NMS, national minimum salary (795.5 dollars/month).

[a] From the national minimum salary to minimum pension. [b] Benefit pension scheme: benefits from the government to provide pension to people who have not provided enough contributions during their working period.

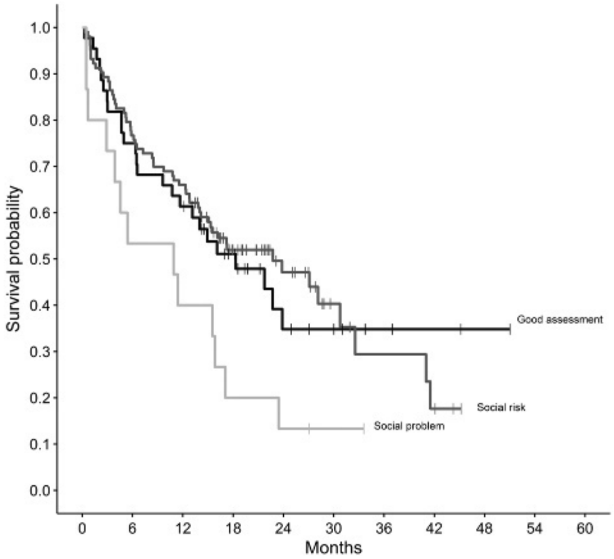


FIGURE 3. *Survival Kaplan-Meier curves according to the social assessment of Social-Familial Evaluation Scale.*

It has been demonstrated that social isolation negatively affects behaviors such as smoking, alcohol consumption, unhealthy dietary habits, and low physical activity[28] and has also been associated with increased cardiovascular mortality.[29] Korda et al[30] found that the lack of social and familial relationships, measured by a social interaction score, was related to a higher risk of unplanned hospital readmissions. It is important to assess social relationships beyond the family environment. Defined as the emotional and functional support that individuals provide to patients, social relationships play a key role in both their quantity and quality.[31] Indeed, evidence shows that health is better in communities with a strong social cohesion than in those with weak ones.[32] In our population, the proportion of patients who did not report any kind of social contact was very small, probably because of the Mediterranean pattern of social/family relationships, which implies close interactions and strengthened social ties and support.[33]

In terms of familial status, the risk of mortality has already been reported to be higher in individuals living alone compared with those living with a partner.[34] It has been hypothesized that single individuals may lack social support and/or motivation for personal care,[35] which can negatively affect the course of the disease. In contrast, family support has been shown to have a protective effect on health.[36]

In our study, we found a high proportion of patients living with physically dependent relatives who may not be able to provide the appropriate care to patients with advanced HF, which might contribute to a higher mortality. It is well known that the health of the caregivers influences the care provided to the patient and, therefore, their prognosis. Informal caregivers experience anxiety, stress, and physical fatigue, because of the great number of activities they have to perform to help patients with HF. This burden contributes to the poor prognosis

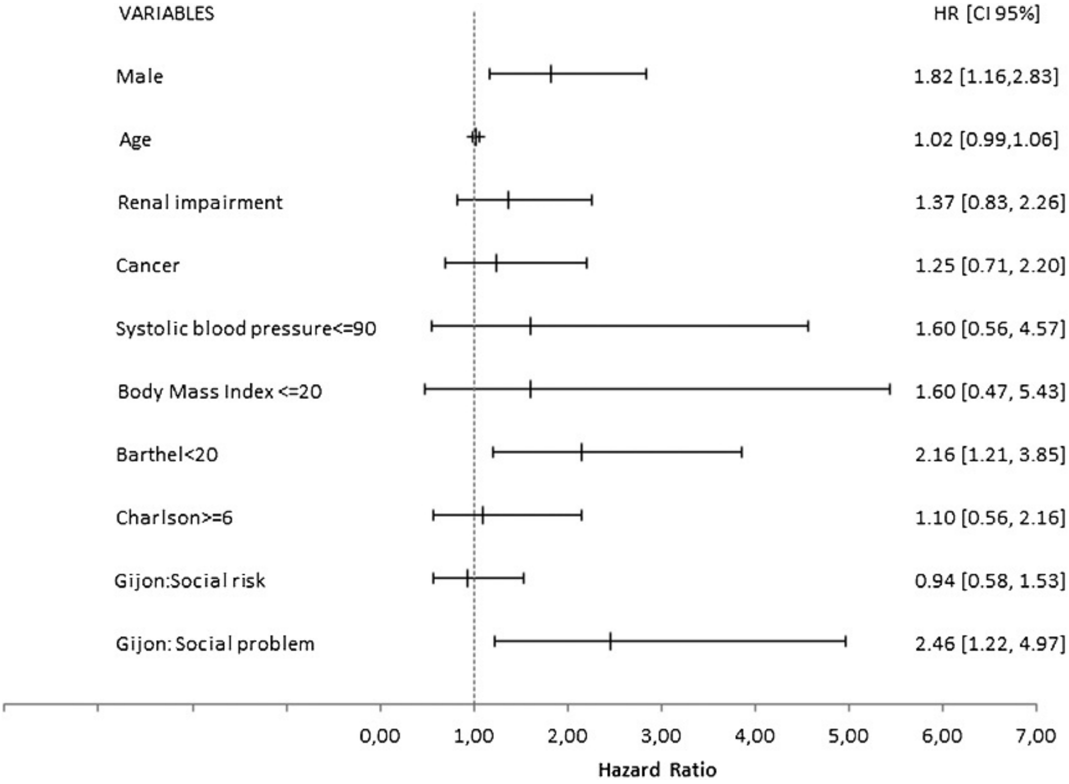


FIGURE 4. *Hazard ratios of factors related to mortality risk in patients with advanced heart failure.*

What's New and Important

- Using the results from this study, the authors illustrate the importance of social issues and their impact on the prognosis of patients with HF.
- Considering social determinants of health would allow healthcare professionals to provide patients in the end stage of HF the necessary support to reduce vulnerability and lengthen their life span.
- The use of an index combining several social items provides a comprehensive way to analyze the impact of social determinants.

in people experiencing advanced HF.[37] In a similar manner to other authors, we observed that patients with HF usually rely on informal caregivers, which implies not only relatives but also friends and neighbors.[38–40]

Regarding housing, authors of a Spanish study showed that patients with HF living in poor conditions such as in a building without an elevator, hot water, a heater, an individual bedroom, an automatic washing machine, and a telephone had a worse clinical situation and were more vulnerable.[41] Although we detected some structural housing barriers in 1 of 3 patients, less than 3% lacked an elevator or a telephone or lived in very poor conditions. It is remarkable that individuals on a waiting list for a nursing home had a very high incidence of mortality, probably because of greater dependence or more serious conditions.

Regarding further variables associated with mortality, we found that patients who were more dependent in basic ADL and those discharged after acute decompensated HF had a higher risk of mortality, similar to what others have found.[42,43] The main contribution of our study is to combine the previously mentioned social determinants to explore the impact of several social factors on mortality in patients with advanced HF by using a comprehensive scale.

Limitations

The results of our study apply to patients with advanced HF and may not be generalized to the general population with HF. The scale to measure social risk has been validated in our population, but some items such as income should be adapted to the reality of other contexts or countries. Nevertheless, the rest of the items are universal and common to any context, and we believe that the concept of social risk is comparable in most developed countries. We also had to deal with the limitations of analyzing information taken from electronic medical records, which were collected for clinical purposes. Another limitation is that we did not include information about ejection fraction N-terminal pro-brain natriuretic peptide (NT-pro-BNP) because these parameters are not used to define advanced HF[6] and may not be essential in the management of patients with HF in the final stages of the disease.

Future Research

Future research is needed to ascertain the precise mechanisms that explain the worse prognosis linked to a higher social risk. Testing these relations in a variety of countries in a multinational study provides information about social risk in varied patients and different contexts.

In conclusion, we showed that patients with advanced HF who are at a social risk have higher rates of mortality irrespective of their comorbidity and functional status. These findings highlight the importance of performing holistic evaluation of patients in the final stages of HF.

Acknowledgments

We acknowledge the work done by the Information System for the Enhancement of Research in Primary Care professionals to provide us with the necessary data to write this article and the support of the Department de Salut de la Generalitat de Catalunya, reference number SLT002/16/00073.

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PLOS ONE

RESEARCH ARTICLE

Living with advanced heart failure: A qualitative study

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Abstract

Introduction

Information about how patients with advanced heart failure (HF) live and cope with their disease remains scarce. The objective of this study was to explore, from phenomenological and holistic perspectives, the experiences of patients suffering from advanced HF, attended at home in the primary care setting in 2018.

Materials and methods

Qualitative study conducted in 4 primary healthcare centers in Barcelona (Spain). Twelve in-depth interviews were conducted in advanced HF patients, aged over 65 and visited regularly at home. We developed a purposeful sampling, accounting for variability in gender, age, and socioeconomic level. Leventhal's framework was used to analyze the interviews.

Results

Participants received insufficient and contradictory information about HF. They talked about their cognitive representation and claimed a better communication with healthcare professionals. Due to their advanced age, subjects considered their daily living limitations to be normal rather than as a consequence of HF. Gender differences in emotional representation were clearly observed. Women considered themselves the keystone of correct family "functioning" and thought that they were not useful if they could not correspond to gendered societal expectations. Cognitive coping strategies included specific diets, taking medication, and registering weight and blood pressure. Nevertheless, they perceived the locus of control as external and felt unable to manage HF progression. Their emotional coping strategies included some activities at home such as watching television and reading. Social support was perceived crucial to the whole process.

Conclusions

Locus of control in advanced HF was perceived as external. Healthcare professionals should adapt emotional health interventions in patients with advanced HF based on a

OPEN ACCESS

Citation: Checa C, Medina-Perucha L, Muñoz M-Á, Verdú-Rotellar JM, Berenguera A (2020) Living with advanced heart failure: A qualitative study. PLoS ONE 15(12): e0243974. https://doi.org/10.1371/journal.pone.0243974

Editor: Hans-Peter Brunner-La Rocca, Maastricht University Medical Center, NETHERLANDS

Received: November 7, 2019

Accepted: December 1, 2020

Published: December 14, 2020

Data Availability Statement: All relevant data are within the manuscript and the figure.

Funding: The principal investigator (Checa C) received the following awards: This study was funded by a grant from IDIAP Jordi Gol i Gurina (reference number 4R17/010) Webpage: https://www.idiapjgol.org/index.php/ca/ This study was developed with the support of the Departament de Salut de la Generalitat de Catalunya, in the call corresponding to 2018 for the granting of subsidies from the Pla Estratègic de Recerca i Innovació en Salut (PERIS) 2019-2021, modality of

"Grants for the intensification of the research activity of health professionals without specialized health training", with the file code SLT008/18/00130. Webpage: http://salutweb.gencat.cat/ca/inici/ The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

Competing interests: The authors have declared that no competing interests exist.

gender perspective. Social support was found to be crucial in facing the disease. Patients reported poor communication with healthcare professionals.

Introduction

Heart failure (HF) disease is a clinical syndrome characterized by being both progressive and physically disabling [1]. In the United States, HF is associated with a high mortality rate, representing one in eight deaths [2].

The final stage of the disease has been defined as the presence of cardiac failure symptoms at minimal effort or rest (hypoperfusion), despite the patient receiving optimal treatment [3]. According to the New York Heart Association (NYHA) scale, advanced HF is represented in stages III and IV, with an ejection fraction less than 30%, and at least one hospitalization in the previous year due to decompensation [4].

Advanced HF presents an unpredictable course that some healthcare professionals may feel insecure treating [5]. Moreover, patients may have a falsely optimistic perception about the progression of the disease and delay end- of-life discussions [6].

Patients suffering from HF have described the condition as uncertain. They find themselves in a situation that entails unexpected acute episodes which makes them feel overwhelmed [7]. This could lead to anxiety or sadness, two emotions described by subjects as having a negative influence on their quality of life [8, 9]. It is therefore relevant to explore patients' perceptions in order to help them manage advanced HF in their day-to-day lives [10].

A previous study found that healthcare professionals focused mainly on curative treatment, patients, however, would also be interested in discussing other issues such as end-of-life topics and management of decompensations [11].

It has also been reported that during the disease's progression, physical, psychological, and social spheres are increasingly affected whilst the spiritual domain fluctuates as patients search for the meaning of life [12].

Gender differences have been described with HF affecting men earlier than women [13]. In addition, a number of studies have highlighted the association between socioeconomic level and mortality [14]. The authors suggest that individuals' circumstances and living conditions, as well as the social support they receive, have an impact on how HF is experienced [15, 16].

Caring for patients suffering from a chronic condition such as advanced HF, requires considering their values and concerns, since such issues could influence their behavior in relation to the disease [17]. Nevertheless, evidence regarding advanced HF patients' daily lives is scarce [18].

There is a lack of information regarding patients' subjective experiences of living with advanced HF which, confirms the difficulty of healthcare professionals in meeting their needs. The objective of this study was to explore, from a phenomenological perspective, experiences of advanced HF patients, attended at home in primary healthcare setting in 2018 in Barcelona (Spain), to understand the lived experience from a holistic perspective.

Materials and methods

Study design and population

We conducted a phenomenological qualitative study with a descriptive-interpretative approach to explore in depth the day-to-day experiences of advanced HF patients. Such an approach was focused from a non-prejudicial perspective. To guarantee confirmability, during

Table 1. Summary of inclusion and exclusion criteria.

Inclusion criteria	Exclusion criteria
Patients diagnosed with HF NYHA III and at least one hospital admission in the previous six months[$], or grade IV	Dementia
Attended at home by primary care professionals	Intellectual disability
Aged > 65 years	Severe psychiatric disorder
	Presence of symptoms that could impede describing the experience

[$] Bjork JB, Alton KK, Georgiopoulou VV, Butler J, Kalogeropoulos AP. Defining Advanced Heart Failure: A Systematic Review of Criteria Used in Clinical Trials. Journal of Cardiac Failure. 2016; 22(7):569–77.

HF: heart failure. NYHA: New York Heart Association.

https://doi.org/10.1371/journal.pone.0243974.t001

data analysis the researchers positioned themselves from the phenomenological reduction standpoint [19].

In this study, cognitive and emotional processes have been framed within Leventhal's common-sense of self-regulation framework [20] and the research team positioned itself from a situative approach.

Patients' eligibility criteria are summarized in Table 1.

Sampling and participant selection strategy

The study was conducted in Barcelona (Spain) in four primary healthcare centers (PHCC) located in four different neighborhoods which reflect the city's variability in socioeconomic status [21]. The characteristics of each PHCC are depicted in Table 2.

We developed a purposeful sampling based on a description of potential participant characteristics extracted from medical records to obtain optimal variety and richness in their discourses. The following variables were taken into account: gender, age, and socioeconomic status. In addition, variables related to the stage of the disease (NYHA III / IV), next of kin, number of household cohabitants, and degree of family relationship was collected. Informative richness and data saturation was achieved.

In each PHCC, a nurse coordinator was assigned to enhance communication between the center and the research team. From February to April in 2018, the coordinator identified patients who met the inclusion criteria and informed the principal investigator. The latter confirmed their suitability for the study and contacted the potential participants by telephone.

In the first contact, the principal investigator explained the study to the patients and emphasized its voluntary and anonymous character. Time was allowed for them to decide whether or not they wished to take part. Once the patients had agreed, appointments were arranged at their homes and informed consents signed before starting the interviews. All the contacted participants agreed to participate in the study.

Table 2. Socioeconomic characteristics of primary health care centers.

Primary health care center	Population	Deprivation index[$]
Dreta Eixample	47594	14.91
Sant Martí	41158	44.52
Clot	25866	35.13
Sant Elies	33727	3.33

[$] Department of Health of Catalonia, Spain. Webpage: http://observatorisalut.gencat.cat/ca/observatori-sobre-els-efectes-de-crisi-en-salut/indicador_socioeconomic_2015/.

https://doi.org/10.1371/journal.pone.0243974.t002

Data collection

All interviews were moderated by the same investigator from the research team, guaranteeing both credibility and homogeneity. The interviewer used open, non-directive questions that were adapted to the participants‘ command of language. The topic guide included six main topics (Table 3): information about the disease, relationship with healthcare professionals, daily life, social support, mood, and the future.

During the interviews, the participants had the opportunity to discuss new topics that they considered relevant to their daily experiences.

The research team started perceiving data saturation after 9 interviews. Finally, twelve interviews were conducted achieving data saturation. The interviews lasted between 20 and 60 minutes and took place at the patients' homes. Interviews were audio-recorded, transcribed verbatim, and contextualized using field notes.

Table 3. Interview guide topics.

Please, we would like to listen to your opinions and experiences on:	
Information about the disease	*When was the first time you heard about heart failure?*
	Who told you?
	What information did they give you regarding the illness and how did you feel?
	What did you think at that time?
Relationship with healthcare professionals	*How is your relationship with healthcare professionals?*
	Do you feel well informed about heart failure? Which professional do you think helps you the most in this?
	How often do professionals come to see you at home because of your health problem?
	What recommendations do professionals give for the treatment of heart failure?
	What are the main difficulties in following the therapeutic recommendations prescribed by primary care professionals?
	What do you think the healthcare professional can do more in relation to heart failure?
	Do you feel that health professionals care about your heart failure?
	How would you like your primary care professionals to help you?
	Do you find something missing in the healthcare attention?
Daily life	*Does your heart disease affect your daily life? In which sense?*
	What activities or strategies help you to live with heart failure in your daily life?
	What activities recommended by healthcare professionals are easiest for you to follow?
	Do you think you can do something to improve your illness?
Social support	*Do you think heart failure affects you in your family and social relationships?*
	In what sense has it affected you?
	How important is social support for you?
	What strategies do you use to try not to let this not affect you?
	How do you feel about that?
Mood	*How do you feel about the disease? Can you describe it to me with a feeling (adjective)?*
	How do you go about trying to feel better? Do you find space to relax?
	Do you think you have learned to take care of your illness?
Future	*How do you imagine the future with the disease?*
	What do you think can happen?
	Has anyone talked to you about this?

https://doi.org/10.1371/journal.pone.0243974.t003

Analysis

Thematic content analysis was used to analyze the interviews, employing steps developed by Berenguera et al. [22]. First, the interviews were read and re-read to attain a pre-analytical insight. Data were then analyzed based on the following steps: a) identification of the main topics, b) fragmentation into units of meaning, c) text codification with mixed strategy: using Leventhal's framework [20] and emerging codes, d) creation of the categories, e) analysis of each category, and f) results elaboration. All members of the research team were involved in the data analyses and consensus was sought for each step. The new framework was discussed with the research team members until a consensus was achieved (triangulation of data). This framework is provided in Fig 1.

Ethical considerations

The study followed the tenets of the Helsinki Declaration and Good Clinical Research Practice [23]. The nurse provided information about the aim and procedures of the study. All participants signed a written informed consent form before starting the interviews. Confidentiality and anonymity were ensured by assigning to each participant a code which was used to identify the transcripts. The project was approved by the Ethics and Clinical Research Committee of the Primary Care Research Institute Jordi Gol (4R17/010). The audio recordings will be securely deleted 5 years after study completion.

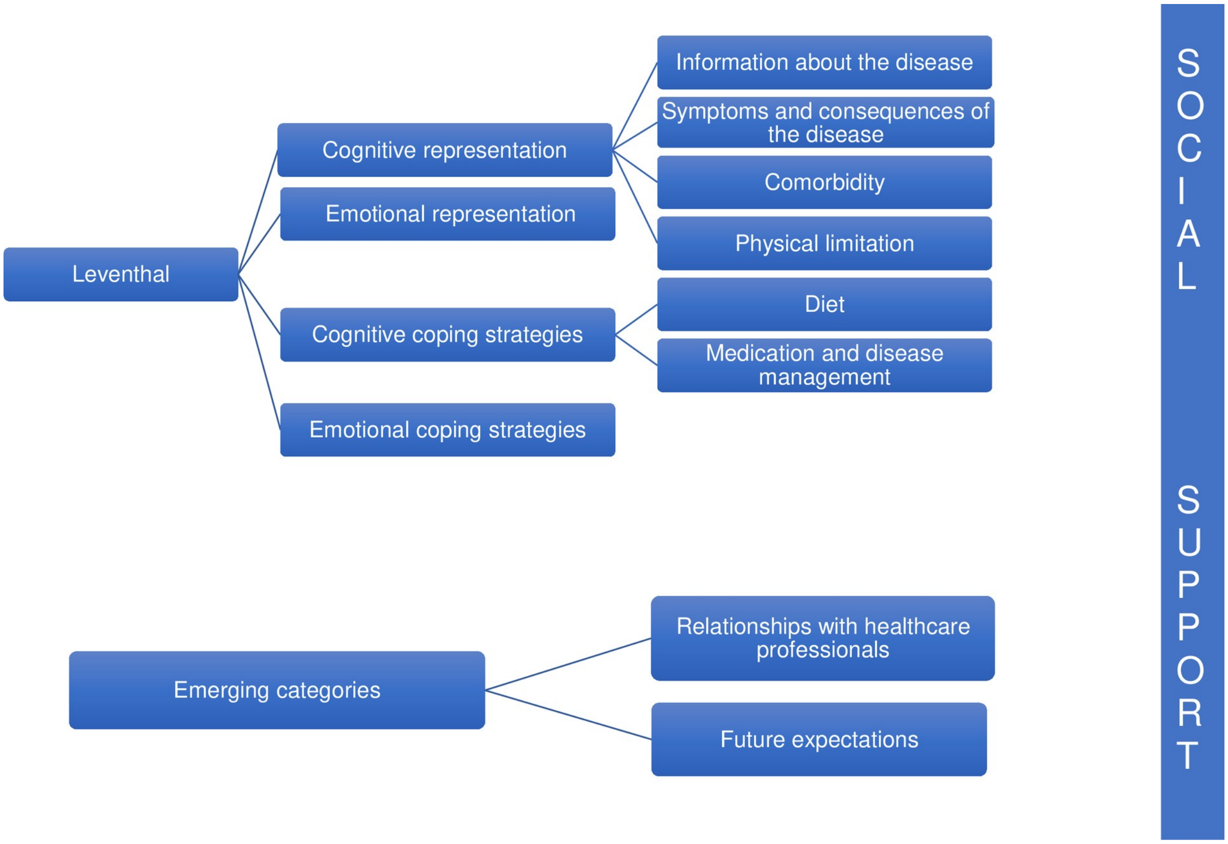

Fig 1. Category tree figure.

https://doi.org/10.1371/journal.pone.0243974.g001

Framework

The Leventhal framework conceptualizes individuals as active "solvers" of their health problems. Initially, individuals tend to receive diagnosis as a threat to their health, and as a result, develop cognitive and emotional representations. Such representations lead to attempts at self-regulation that may involve different coping strategies that interact with each other. Individuals then assess the consequences of their actions and self-regulate their response in a system of continuous feedback [20].

Additionally, the research team was positioned from the situative approach. This is characterized by their were being involved in the phenomenon, learning from it progressively. The learning process is gradually improved due to the researchers' desire to participate in the investigation and increased appearance of feelings of belonging to the study phenomenon [24].

Results

Participant characteristics and codification are available in Table 4. Results are presented following Leventhal's framework (cognitive and emotional representations, cognitive coping and emotional strategies, and social support) and emerging codes (healthcare professional relationship and expected future).

Leventhal framework

1. Cognitive representation. Cognitive representations refer to how patients first experienced HF, and its consequences, with respect to their daily life (symptoms, comorbidity, and physical limitation).

1.1 Information about the disease. The participants explained that they were diagnosed with HF after a long period of decompensations. During the interviews, it was observed that they tended to normalize HF symptoms, and even referred at them as a consequence of aging. The participants first received information about HF from healthcare specialists while in hospital for an exacerbation. They claimed that both information and guidance on how to manage the disease in daily life were scarce. Details provided included the possibility of an intervention which was understood as a good sign and that the heart could be "repaired".

Table 4. Clinical and social characteristics of participants.

Area	Deprivation index	Gender	Age	Stage of the NYHA classification	Academic level	Next of kin	Number of cohabitants$^{\$}$	Verbatim code
Dreta Eixample	14.91	Women	81	III	University	Husband	2	MM81
			88	III	Secondary	Son	3	LT88
		Men	86	IV	University	Wife	2	JB86
			89	III	Elementary	Wife	2	ES89
Sant Martí	44.52	Women	77	III	Secondary	Daughter	1	AR77
			79	IV	Elementary	Husband	2	JM79
		Men	70	IV	Elementary	Wife	4	AM70
			82	IV	No studies	Wife	2	JM82
			92	IV	No studies	Daughter	3	VS92
Sant Elies	3.33	Women	74	III	Elementary	Daughter	6	CG74
		Men	76	III	Secondary	Son	2	RP76
Clot	35.13	Women	92	IV	No studies	Daughter	2	DA92

$^{\$}$Total number of cohabitants including the participant. NYHA: New York Heart Association.

https://doi.org/10.1371/journal.pone.0243974.t004

The patients generally felt that healthcare professionals employed a wide range of technical language that made it difficult for them to understand full explanations. As a result, they tended to adopt a passive attitude towards the information they were receiving and were often excluded from any dialogue with healthcare professionals, so there was no option for a shared decision-making process.

> *JM82 "They say I have heart failure. . . but they talk to each other [between healthcare professionals] . . . they said nothing to me. . . they auscultate my back and made their conclusions, I don't know. . ."*

The locus of control in advanced HF was perceived as external. Patients sought an explanation for their illness, and the majority considered the contributing factors to be beyond their control. Such a situation led to feelings of desperation and impotence. Only two participants referred to the fact that external causes could lead to HF: hereditary issues and a poor lifestyle.

> *CG74 "What I have is a hereditary disease. . . we all suffer from the heart in my family, we get the tests and half of my family is ill. . . our ancestors? Could have left us money but no! They left us diseases!"*

> *DA92 "I don't know how I can be ill. . . I always eat well, because I try to take care of myself . . . I had sugar on my blood and now I don't. . . I used to have cholesterol and now I don't. . . I was on a diet. . . I don't know why I have this"*

1.2 Symptoms and consequences of the disease. Patients were provided with descriptions of various techniques to treat HF such as catheterization, pacemaker implants and a cardioverter-defibrillator. They did not, however, consider such interventions as forming part of their chronic treatment but merely occasional measures to improve their condition. In fact, they did not receive any explanations about which intervention was the most appropriate and its relevance.

Furthermore, the participants felt unable to manage decompensations. Advanced HF involves many hospitalizations between stable periods, and patients admitted to sometimes delaying admission, or even refusing to attend, as way of rebelling against the disease and temporarily breaking treatment adherence.

> *JM82 "I have to go a lot to the hospital and stay there for days. Every two or three months I go. . . Now I am. . . I don't go now because I am a stubborn person because if not, I would be in the hospital again. Now I feel like I should be in the hospital"*

Suffering from HF involves everyday symptoms such as chest pain, breathlessness, edema, and marked tiredness that participants sometimes referred to as part of aging. All of them, however, mentioned pulmonary congestion as aggravating baseline symptoms.

During the interviews, symptoms were highlighted as potentially representing a considerable emotional burden.

> *JB86 "When I walk I get tired. . . and I thought at the beginning that I couldn't live like this. . . and of course, it was the heart what was damaged. . . the pacemaker helps a lot, I have had it from twelve years or so, but I still feel tired".*

1.3 Comorbidity. Besides advanced HF, participants talked about other conditions that worried them and had a negative impact on their daily lives. Almost all the patients mentioned diabetes and most of them renal failure. All the comorbidities referred to were considered as part of the aging process and not lifestyle factors. Participants explained interactions between diseases and treatments that made it even more difficult to cope with the whole experience.

> *ES89 "As you get older, the diseases appear. . . because on top of that I have diabetes but type II. . . then they (healthcare professionals) saw that my kidney is not working normally . . . and. . . if I take diuretics and. . . this is constantly happening to me. . . then I found that it kills my kidney. . . and if someday I need cortisone this unevens sugar! So, you have to calculate the insulin. . . I always check my sugar level. . . one day my wife found me unconscious and my sugar level was 26!"*

1.4 Physical limitation. During the interviews, all participants described difficulties in carrying out their daily activities and remarked this was their principal day-to-day limitation. They commented that they depended on their family or caregivers to help them with basic tasks such as bathing and dressing.

Furthermore, there was a marked concern among women about limitations in carrying out housework, and they emphasized their wish to gain physical independence in order to manage it better. The burden of physical limitations was different for men since they referred to being adapted to the disease and, moreover, being used to be cared by others.

Physical limitations in both genders were generally attributed to aging and not necessarily to the disease itself. However, patients sometimes felt an increased baseline tiredness which they ascribed to HF exacerbation and were able to distinguish the periods they occurred.

The discrepancy between health recommendations and the participants' own physical capacity was highlighted when they commented that some of the non-pharmacological recommendations (maintaining physical activity and weight themselves) were impracticable due to baseline symptoms and physical limitations.

> *AR77 ". . . I am also older, so I am more tired. . . not for just a walk. . .no, but at home, there are a lot of things that I would like to do and I can't, for example cleaning mirrors, the kitchen, the bath. . . professionals told me to walk!!! hahaha I can't!!!" (Woman)*

> *VS92 "Because don't move too much. . . I do. . . I wash. . . I shower. . . (coughs). . . Slowly I shower, I don't move from here. . . There are people who cannot have a relaxed life, of course. . . A person who cannot stop from moving. . . But if I have no need! why should I go for a walk? Or do things? I have no need of this" (Man)*

2. Emotional representation. Emotional representations refer to patients' emotional experiences related to living with advanced HF.

For the participants, advanced HF had repercussions on their mental health. All the women experienced sadness and resignation when diagnosed. They described how they felt unfortunate, and were concerned about the future and how their disease could affect their roles within the family. The female participants also admitted to feeling depressed and lonely, and sometimes suffering from anxiety. On the other hand, men appeared to be more relaxed and even optimistic about being cured.

> *MM81 "so at first I felt bad, well very bad. . . very sad. . . I thought a lot about this. . . why it happened to me?" (Woman).*

> *AM70 ". . .well, it happens to me (think a lot at night) . . . because all my family goes to bed and in that moment I feel alone I think. . . it is not depression, I think it is not. . . but it is just*

> *think and think. . . but then I feel I cannot live like this! I cannot live with fear because in this case it will be better to die! so generally I am calmed. . ." (Man).*
>
> *DA92 "I'm getting worse and worse. . . I have depression! I am exhausted with everything. I used to do many things at home, dresses, quilts. . . now I do not even want to do anything anymore, how do I feel? Bad. . . I'm not good doing anything, I used to do everything! Now I have nothing left" (woman).*

Both genders referred to frustration, feeling they were a burden for others and dependent on them for basic daily activities.

Emotional and cognitive representations are not necessarily independent from each other, and could be in constant interaction to create the representation of the disease.

3. Cognitive coping strategies. This section describes cognitive coping strategies to improve physical well-being through diet, medication, and disease management.

3.1 Diet. In order to cope with the disease and prevent decompensations, some participants mentioned they could partially avert congestive symptoms with diet. This coping strategy was perceived as simple adherence to healthy food guidelines. The participants followed general recommendations, a hypo-sodic diet, and water restriction. One participant felt these were too strict since, in addition to HF guidelines, he followed others for his comorbidities.

> *AM70 "Well, especially the diet. . . because in the last analysis, besides the sugar, there was also the salt. . . they are suppressing everything! This is too much. Sometimes they even ban beer without alcohol. . ."*
>
> *CG74 "I have to take care of food, that's normal. . . I cannot say that they do not tell me. . . because they have told me 200 times. . . that I should not eat salt, that I should eat vegetables, fruit. . . I should not eat sausages. . . it is easy for me, I eat everything. . . for example, I made a stew, so I cook it light with only vegetables."*

3.2 Medication and disease management. Another way to prevent congestive symptoms was through medication. All participants said that they had to cope with this issue, and highlighted the fact that they had to deal with constant changes in medications and doses. They referred to diuretics as a common drug for HF, and even though intake was generally easy, considerable discomfort could arise due to the need to frequently urinate.

> *VS92 "You have to endure. . . you cannot make any effort, having a peaceful life. . . you go day by day because if you make some kind of effort you will feel worse! And now the pills. . . they (professionals) change a lot my medication. . . I have had a really bad year. . . They say one at first, then other. . . they drive me crazy! For the moment, I take a lot of pills and that's all"*

For some participants, having their blood pressure taken was a crucially objective sign of good disease management, as was weight measurement when possible. Only one participant talked about quitting unhealthy habits such as smoking as a first step for good HF management.

All of them sought a quiet life with no physical effort due to baseline symptoms.

> *ES89 "Well I take this as a routine. . . I am a very pragmatic person. . . I wake up, I weigh myself, I take the pills. . . the diuretic one first. . .that's a recommendation, I measure my blood pressure, I measure my sugar levels. . . I have to have everything under control, sometimes it gets wrong in one way, sometimes to another. . ."*

4. Emotional coping strategies. Emotional coping strategies refer to how advanced HF patients cope with emotions and improve their daily lives.

Advanced HF affects had repercussions in mental health, and all the participants emphasized some strategies to enhance it. Such strategies were based on the completion of domestic activities (watching television, reading. . .) positive thinking and social relationships. They said that these activities allowed them to keep their minds concentrated and focus attention away from the disease.

> *AR77 ". . . I try to speak with my friends, I have friends I speak with, they come here, well, she is widow now too. . . before me. . . and we talk a lot. . . I get distracted. . . when I think too much I switch on the TV and I watch it or I do an alphabet soup. . . I try not to think too much. . . I take a book and read. . . I try also not to worry my family. . .they call me "mama, how are you?" "Fine, dear. . ."*

The participants also reported that being grateful, for example, for living in their own homes and maintaining social relationships, provided benefits with respect to coping with emotions.

> *VS92 "What can you do? Be angry? Yes. . . hahaha. . . What I have to do is be grateful for being here! There are many people that cannot explain this and I am here now. You have to be always grateful. It is not worth to think too much. . . you have to be adaptable"*

Some patients added that minimizing HF symptoms and consequences in family relationships helped divert attention from their health and maintain better communication with their relatives. For all of them, social support was crucial in coping with emotions.

A few explained that religion alleviated their suffering and provided acceptance. They explained that God helped them to overcome their daily lives by bringing peace of mind. For some participants religion was very important, and they gained comfort practicing its rituals.

> *MM81 "this suffering. . . what I am suffering now I do not know if many people would endure it. . . and I have faith. . . because if not. . . you will be buried. . . God helped me because I was not well, I did not do anything wrong in life. . ."*

5. Social support. Living with advanced HF is a strenuous process that has both physical and psychological consequences. From the interviews, social support was found to be a transversal category that played a key role in the patients' experiences of HF.

All the participants reported that good social support brought them relief and strength. In fact, those who felt they did not have enough expressed stronger feelings of depression and poorer quality of life.

> JM79 "*Well, my sister helped me a lot. You have to think that she came here every day, and she had her job. . . And I came every day to wash myself, to dress me. . . Well, to dress me. . . To change me this, to change that. . . Yes, she. . . We must be very grateful to her. Because, who did it to me?"*

Social support came mainly from the participants' families although some subjects said that friends were also important. Despite having more friends prior to diagnosis, the quality of the relationships was greater at the moment of the interviews. For most participants, being ill had led to generating stronger links with some people and the loss of other friendships. They valued meaningful relationships and found them helpful in coping with all aspects of the disease (both cognitive and emotional).

The patients also considered formal caregiver support as essential in order to perform basic daily living.

> *LT88 "I will need 2 or 3 hours more per week of help (carers), more than anything for the company! Because sometimes these girls that come, when we have finished showering or fixing my feet. . . I tell them, look we will talk for a while! And sometimes when my grandchild comes, I tell him, hang me that, do me that. . . and that also affects me because, well, if you want to do something, you have to wait for someone, you should always have someone.. . . that helps you, that's what has depressed me quite a lot, you know?"*

6. Emerging categories. Categories were identified that did not fit within the Leventhal Model. These were related to relationships with healthcare professionals and participants' expectations for the future.

6.1 Relationships with healthcare professionals. During the interviews, the participants emphasized the importance of a trusting relationship with the healthcare professionals. They valued such qualities as kindness, affection, honesty, and compassion. In general, the participants felt that primary healthcare professionals were concerned about their health status. In periods of stability, however, the patients perceived that they were less involved with the healthcare system, which led to a feeling of loss of control with respect to the disease.

> *AR77 "Time ago professionals took a lot of care, but now they see that I am very stable. . . And then I do not. . . I do not think they are very worried! "*

Only one participant reported having a negative relationship with primary healthcare professionals and little contact. This participant highlighted the fact that a trusting relationship with primary healthcare professionals was more valuable than medication. The same individual remarked on the importance of the longitudinal characteristics of the primary care services provided by scheduled home visits.

> *JM82 "Because they have told me 20 times that the doctors would come and nobody comes here. No one comes! Lie! They tell you there in the hospital, or in the outpatient clinic, whatever. . . But here nobody comes! I believe, I have always believed, I have always thought that good personal treatment would cure more than pills. They would have to treat you with more humanely. Sure, I don't have studies to explain this. . .I think it but I cannot explain. . . I am very basic, illiterate. . . I can not. . . Well, that would have to be more human, and give a more human treatment to the patient, the patient. . . Sometimes we are looking forward to a humane visit"*

In relation to specialist healthcare professionals in hospital, the participants had a trusting relationship with their cardiologist. They added that having a contact phone number to reach a healthcare professional provided comfort. Advanced HF patients found the emergency departments to be chaotic, noisy, uncomfortable, and unsuitable for their needs. They preferred scheduled options such as planned hospital admissions or home treatment.

All participants reported receiving home visits from primary healthcare professionals who helped them manage the disease. Nevertheless, they perceived that the most specialized HF care was provided by a cardiologist during scheduled appointments, and when admitted to hospital wards during a decompensation.

6.2 Future expectations. The participants also wondered about their future and found it predictable. Although they claimed that no healthcare professional had explained to them how they would feel, and the care they would need, they said they did not expect to be cured and were aware they would be more physically dependent. They also understood physical dependency as a normal state of aging.

> *MM81 "a future. . . very long future I do not have it, dear. A very long future I do not expect. . . I have to ensure that in the future I will not lose joy. . . do not miss. . . the future I cannot say. . .I have to think about living the day to day. . .Every day I will be building a bit of that future. . . Professionals don't talk to me about it because. . . what can they tell me*?. . . *What can you tell me*?

In addition, all the emotional coping strategies such as positive thinking, fostering meaningful relationships, and the completion of household activities played a key role in facing the future.

Only one participant avoided receiving information about the future, as a way of coping with her fear of an unfavorable progression of the disease.

> *JM79 "I can't imagine my future and I don't ask information about it. . . you know what*? *I don't want to know what is going to happen"*

Discussion

Summary of main results

Participants described receiving insufficient and contradictory information about HF and referred to the fact that diagnoses was usually made during exacerbation in emergency rooms. For most of them, limitations in daily living were perceived as normal given their advanced age rather than being attributed to their condition. Since being older is usually associated with suffering and physical deterioration, the participants felt resigned to their situation, and normalized their deteriorated health status.

Regarding emotional representation, gender differences were clearly observed. Women considered themselves as playing a crucial role in the "proper functioning" of the family.

The participants in our study talked also about cognitive representation after diagnosis, and claimed they needed better communication with healthcare professionals. Cognitive coping strategies included following a diet, taking medication, and registering some objective measurements such as weight and blood pressure. Despite such strategies, the patients felt that the locus of control was external and considered themselves unable to manage HF progression.

Emotional coping strategies to manage HF included some activities at home such as watching television and reading.

Social support was perceived as crucial to the whole process in coping with the disease.

Discussion of the main results

Early diagnosis is known to be crucial in order to start proper treatment in HF patients [25]. All our participants had been diagnosed after a considerable period of time during which they had normalized HF symptoms and attributed them to aging. Diagnosis normally takes place in hospital emergency departments when patients need to be treated as a consequence of an exacerbation of the disease [26] as was the case of our sample.

Such a context does not always guarantee the necessary conditions for fluid communication, patients can feel overwhelmed since they do not fully understand the extent of their condition [27]. Moreover, it has been demonstrated that the way in which physicians provide information is crucial since this has an impact on understanding and treatment adherence [28]. We therefore consider it important to create specific protocols to communicate diagnoses in emergency department settings, and specifically for HF in acute decompensation situations, since patients often resort to the emergency rooms without a previous diagnosis.

With respect to developing such protocols, it should be noted that patients have reported preferring to receive a diagnosis in quieter and more comfortable venues than emergency rooms. A specific location should therefore be allocated to deliver this type of news so that patients are in a calmer environment and thus feel freer to ask questions and become more involved in the health process [29].

Regarding our participants, following diagnosis they did not usually have well established follow-up appointments with primary healthcare services. Consequently, they resorted to emergency services when they felt unwell. It has been observed that patients lacking primary healthcare follow-up have a higher probability of being re-admitted to hospital [30]. Such a situation could be aggravated by poor coordination between hospitals and primary healthcare professionals leading to misinformation in primary healthcare regarding the patient's current health status after hospital admission [31]. Primary care home-schedule appointments for patients in stable periods need to be set up in order to improve communication and promote empowerment of advanced HF patients.

Although primary healthcare is more accessible than other healthcare settings, and takes into account how patients feel [32], subjects feel safer in hospitals [33]. This could be due to the fact that they tend to prefer specialized care to manage their decompensations. Even though primary care offers a better holistic approach when evaluating overall health, hospitals provide a wide range of complementary measures and techniques. Nevertheless, we found that patients tried to be admitted as little as possible because of the disruption to their lives [34].

Locus of control is a concept used to represent the degree of influence that individuals perceive they have over their health. The internal locus of control refers to subjects thinking that their personal decisions, for instance, diet, could influence their health. The external locus is the belief that one's health is out of one's control [35] which can lead to a wide range of negative emotions.

The locus of control in our participants was mainly perceived as external since they felt they had no control over the progression of the disease. They considered the course of the disease and its decompensations would not be modified by lifestyle changes, for instance, a hyposodic diet. Apart from a study in HF patients which reported that patients felt able to influence the course of the disease [36], there is no further information about the locus of control in advanced HF patients.

An external locus of control could also be related to a lack of empowerment which is not always facilitated by healthcare professionals. Our participants explained that some recommendations given by health professionals (e.g. physical exercise) did not correspond to their current status and could not be performed. This could diminish the relationship of trust with the professionals and lead to a decrease in treatment adherence [37]. We consider it crucial that recommendations be adapted to the patients' functional status.

In this context, "virtual communities of practice" have been used among health professionals to share experiences about patients and better understand how to empower them. Such communities have been well accepted and are a way of facilitating peer learning [38]. It could be useful to implement this tool in daily practice.

Social support plays a key role and contributes to disease management [39]. Caregivers are considered to be crucial following hospital discharge, they are a source of comfort, advocating, and even acting as a mediator between patient and healthcare provider [40]. We found social support to be critical in motivating patients to cope with the disease and observed a strong link between lack of social support, sadness, and a worse perceived health status [41]. It is plausible to think that, in addition to the operational help that social support can provide, patients could receive informal emotional support from caregivers, family and friends. In this regard, it was found that patients with good social support had better levels of mental health and self-care [42].

It is necessary, therefore, to create programs to help individuals with limited social support improve their levels of adherence, mental health, and self-care. Indeed, a specific intervention based on coping strategies such as relaxation training, cognitive restructuring, and problem solving in patients with lack of social support has shown to be not only cost-effective, but also instrumental in improving quality of life and reducing depression [43].

In terms of emotions, we found that women expressed feelings of sadness, loneliness, and even desperation caused by their marked physical limitations. Such situation is probably due to their socially assigned caregiving/reproductive roles which cannot be fulfilled due to the basal symptoms and physical decline of advanced HF [44]. Whilst it is accepted by both genders that men are weaker when they get sick and become more dependent [45], our male participants claimed to be relaxed and well-adapted to the disease. Such a difference could be partially explained by the tendency of men in patriarchal societies to want to appear stronger and not express emotions [46]. All of which could result in depressive feelings not being expressed thus leading to a perceived "good" adjustment to illness. Nevertheless, we are not aware of any previous authors examining in depth emotional gender differences and masculinity in patients with advanced HF and its impact in healthcare.

These gender-emotional differences have, however, been studied in other conditions such as chronic pain. The authors concluded that there is a gender bias in treatment management with women being generally undertreated [47]. Specific training regarding gender perspectives for health professionals could provide a better healthcare approach to emotions.

This study on advanced heart failure patients provides new information concerning the experience of living with the disease, and could help healthcare professionals to understand needs, preferences, and expectations in order to improve the care provided.

Strengths and limitations

The main strength of this research is that we could explore in depth the experience of patients living with advanced HF. Furthermore, the interviews held at their homes provided the opportunity to collect data in their context. We believe this to be of value as narratives can be richer and more truthful regarding the patients' experiences. In addition, the analysis was performed by a multidisciplinary research team and data were mapped based on a theoretical model.

Our study was based on theoretical-methodological and technical concordance in order to properly achieve the main objective. The rigorous procedures employed (triangulation, data saturation, and the characteristic flexibility of qualitative methodology) ensured the validity of the results. Caution is needed when extrapolating these results to other populations. Nevertheless, we consider that the experience of advanced HF in our participants may be transferable to those in most developed countries. Although the sample was only 12 participants it was sufficient to obtain results about their experience. In phenomenology, small samples can give considerable information regarding individuals' perceptions. Ours sample was taken from an elderly population so it was common for them to present comorbidities. We believe that this should be taken into account when understanding their experiences of health and illness as a whole.

Conclusions

Patients with advanced HF consider the symptoms and consequences of the disease as part of the process of aging more than the disease itself. The locus of control of the disease was perceived as external because participants felt that they could not influence the course of HF.

We found differences in emotional representation between genders. Women referred more to depressive symptoms while men claimed to be calmer and even hoped to be cured. Healthcare professionals should adapt emotional health interventions in patients with advanced HF based on a gender perspective.

Regarding cognitive coping strategies, patients found treatment generally easy to follow, but some lifestyle recommendations could not be performed due to the patients' physical limitations. In all the process, social support was considered crucial when confronting advanced HF.

Participants reported poor communication with healthcare professionals.

Clinical implications

- Patients believe that the information provided by professionals is scarce. Therefore, it is necessary to involve patients in care and dialogue to provide all the necessary guidance. Furthermore, patients suffering from advanced heart failure value a trusting communication and optimum relationships with healthcare professionals.
- Since social support is crucial for patients with this disease, it should always be taken assessed in clinical evaluations.
- Professionals should take into account the emotional differences between genders and incorporate mental health evaluations.
- Since the locus of control is perceived as external, professionals should encourage patients to take control of the disease and give them recommendations they feel they can perform.

Further research

- In view of the fact that patients may feel excluded from the care process, we consider it crucial to develop patient and public involvement in research (PPI) strategies.
- More research should be done regarding the locus of control and its repercussions in patients with advanced HF.
- Emotional differences between genders should be investigated in depth.
- Given that HF suffering and symptoms are considered normal in the elderly, it would be interesting to investigate the impact of this perception on the disease.

Acknowledgments

We would like to thank all the participants who shared their experiences in this study.

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International Journal of
Environmental Research and Public Health

Review

Effectiveness and Cost-Effectiveness of Case Management in Advanced Heart Failure Patients Attended in Primary Care: A Systematic Review and Meta-Analysis

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Citation: Checa, C.; Canelo-Aybar, C.; Suclupe, S.; Ginesta-López, D.; Berenguera, A.; Castells, X.; Brotons, C.; Posso, M. Effectiveness and Cost-Effectiveness of Case Management in Advanced Heart Failure Patients Attended in Primary Care: A Systematic Review and Meta-Analysis. *Int. J. Environ. Res. Public Health* **2022**, *19*, 13823. https://doi.org/10.3390/ijerph192113823

Academic Editor: Jayasree (Joy) Basu

Received: 25 September 2022
Accepted: 21 October 2022
Published: 24 October 2022

Abstract: Aims: Nurse-led case management (CM) may improve quality of life (QoL) for advanced heart failure (HF) patients. No systematic review (SR), however, has summarized its effectiveness/cost-effectiveness. We aimed to evaluate the effect of such programs in primary care settings in advanced HF patients. We examined and summarized evidence on QoL, mortality, hospitalization, self-care, and cost-effectiveness. Methods and results: The MEDLINE, CINAHL, Embase, Clinical Trials, WHO, Registry of International Clinical Trials, and Central Cochrane were searched up to March 2022. The Consensus Health Economic Criteria instrument to assess risk-of-bias in economic evaluations, Cochrane risk-of-bias 2 for clinical trials, and an adaptation of Robins-I for quasi-experimental and cohort studies were employed. Results from nurse-led CM programs did not reduce mortality (RR 0.78, 95% CI 0.53 to 1.15; participants = 1345; studies = 6; $I^2 = 47\%$). They decreased HF hospitalizations (HR 0.79, 95% CI 0.68 to 0.91; participants = 1989; studies = 8; $I^2 = 0\%$) and all-cause ones (HR 0.73, 95% CI 0.60 to 0.89; participants = 1012; studies = 5; $I^2 = 36\%$). QoL improved in medium-term follow-up (SMD 0.18, 95% CI 0.05 to 0.32; participants = 1228; studies = 8; $I^2 = 28\%$), and self-care was not statistically significant improved (SMD 0.66, 95% CI −0.84 to 2.17; participants = 450; studies = 3; $I^2 = 97\%$). A wide variety of costs ranging from USD 4975 to EUR 27,538 was observed. The intervention was cost-effective at ≤EUR 60,000/QALY. Conclusions: Nurse-led CM reduces all-cause hospital admissions and HF hospitalizations but not all-cause mortality. QoL improved at medium-term follow-up. Such programs could be cost-effective in high-income countries.

Keywords: case management; advanced heart failure; cost-effectiveness; meta-analyses; mortality; quality of life; hospital admissions; self-care

1. Introduction

Heart failure (HF) occurs when blood flow is insufficient to meet tissue metabolic needs [1]. Advanced HF (stage D according to America Guidelines) is defined by the presence of symptoms at minimal effort/rest, or hypoperfusion, despite optimal treatment [2,3]. The New York Heart Association (NYHA) also provides a broadly used method of classifying HF severity; advanced HF corresponds to classes III to IV [4]. In 2017, data from the European Heart Failure Registry reported 8.1% and 28.1% for 12-month mortality and hospitalization, respectively, with NYHA III and IV representing a strong predictor of mortality [5].

Advanced HF involves multiple hospital admissions and increased costs for both acute and stable phases [2]. An economic study performed in an HF population in the United States estimated a lifetime cost of USD 126,819 per patient representing around 1–2% of the healthcare budget [6].

Furthermore, quality of life (QoL) is also affected. A systematic review indicated moderate/poor QoL, particularly in elderly and female populations [7], and a greater deterioration in those with advanced HF [8].

One strategy is the nurse-led case management (CM) model, which is a collaborative process of assessment, planning, facilitation, care coordination, evaluation, and advocacy for options and services to meet an individual's and family's comprehensive health needs through communication and available resources to promote patient safety, quality of care, and cost-effective outcomes [9,10].

Implemented in community settings, it has achieved improvements in HF-related outcomes and QoL. A 2019 Cochrane systematic review summarized the evidence of all types of CM models for HF patients in all stages. It suggested they be effective in reducing hospitalizations and all-cause mortality [11].

Nevertheless, the effectiveness of CM in advanced HF-related outcomes is controversial. Rogers et al. reported that an interdisciplinary intervention could improve QoL [12] whilst another study reported it did not ameliorate hospitalizations/mortality [13].

To date, no systematic review has summarized the effect of nurse-led CM models on an advanced HF population. We aimed therefore to evaluate the effect of such programs in primary care settings for advanced HF patients and their effect on QoL, mortality, hospitalization, costs, and cost-effectiveness outcomes.

2. Methods

2.1. Study Inclusion Criteria

2.1.1. Types of Design

Prospective studies with control groups as randomized controlled trials, quasi-experimental, and cohort studies.

2.1.2. Types of Participants

Patients $\geq$18 years with advanced HF, III/IV NYHA classification, stage D of the American College of Cardiology Foundation/American Heart Association (ACCF/AHA), or under palliative care.

2.1.3. Types of Interventions

Inclusion criteria:

- Studies where the nurse-led CM model effect was measured.
- Community interventions including those commencing in hospital.

Exclusion criteria:

- Nurse-led CM interventions developed only in hospitals.
- Cardiac rehabilitation programs, unless providing elements of nurse-led CM.
- Community interventions from specialized HF clinics directed by cardiologists.
- Only one educational session, without follow-up phone calls/patient interaction.

2.1.4. Type of Comparator/Control

Studies comparing the intervention with usual care or another nurse-led CM program within primary/community care.

2.1.5. Outcomes

Primary Outcome

Nurse-led CM program effects on mortality in primary care settings on advanced HF patients.

Secondary Outcomes

Results regarding QoL, hospitalization, adherence to treatment, undesirable effects, costs, and cost-effectiveness.

Types of Outcome Measures

- QoL measured by EuroQol-5D, SF-8, SF-36, and the Kansas City Cardiomyopathy Questionnaire (KCCQ) scales, etc.
- All-cause and HF mortality.
- Number of HF hospitalizations or for any other cause during follow-up.
- Self-care measured by the Appraisal of Self-care Agency (ASA) Scale, European Heart Failure Self-care Behavior Scale, and Self-care of Heart Failure Index.
- Costs associated with health resources.
- Cost per QALY (quality-adjusted life year), cost per year of life gained.

Outcomes were measured by follow-up time when available (<6 months, 6–12 months, >12 months), age, and type of consultations (home visits/telemedicine).

2.2. Search Methods

2.2.1. Electronic Searches

Searches were performed with MEDLINE, CINAHL, Embase, Clinical Trials, WHO, Registry of International Clinical Trials, and Central Cochrane. The World Health Organization's International Clinical Trials Registry (ICTRP) platform (http://apps.who.int/trialsearch/, accessed on 24 March 2022), and the ISRCT registry (https://www.isrctn.com/, accessed on 24 March 2022) were used. One hundred ongoing studies were identified by the USA ClinicalTrials.gov registry (https://ClinicalTrials.gov/, accessed on 24 March 2022), however, there were no partial results published and they were excluded.

The database was EndNote χ^2 software. Publications were included up to March 2022 (See Appendix A).

2.2.2. Other Resources

A manual inspection of the references in previous systematic reviews of HF patient nurse-led CM models was conducted. Gray literature was reviewed, and experts consulted.

2.3. Data Collection and Analysis

2.3.1. Study Selection

Initial screening of titles/abstracts was performed by a reviewer. A random sample of 20% of the retrieved references was evaluated by a second reviewer in order to guarantee the quality of the process.

Two reviewers then independently assessed eligibility of the 405 studies based on full-text reading. In case of discrepancy, there were consensus sessions. The Rayyan program [14] was employed throughout.

A PRISMA flow chart depicts the study selection (Figure 1). For excluded studies at the full-text level, see Supplementary Material Table S1.

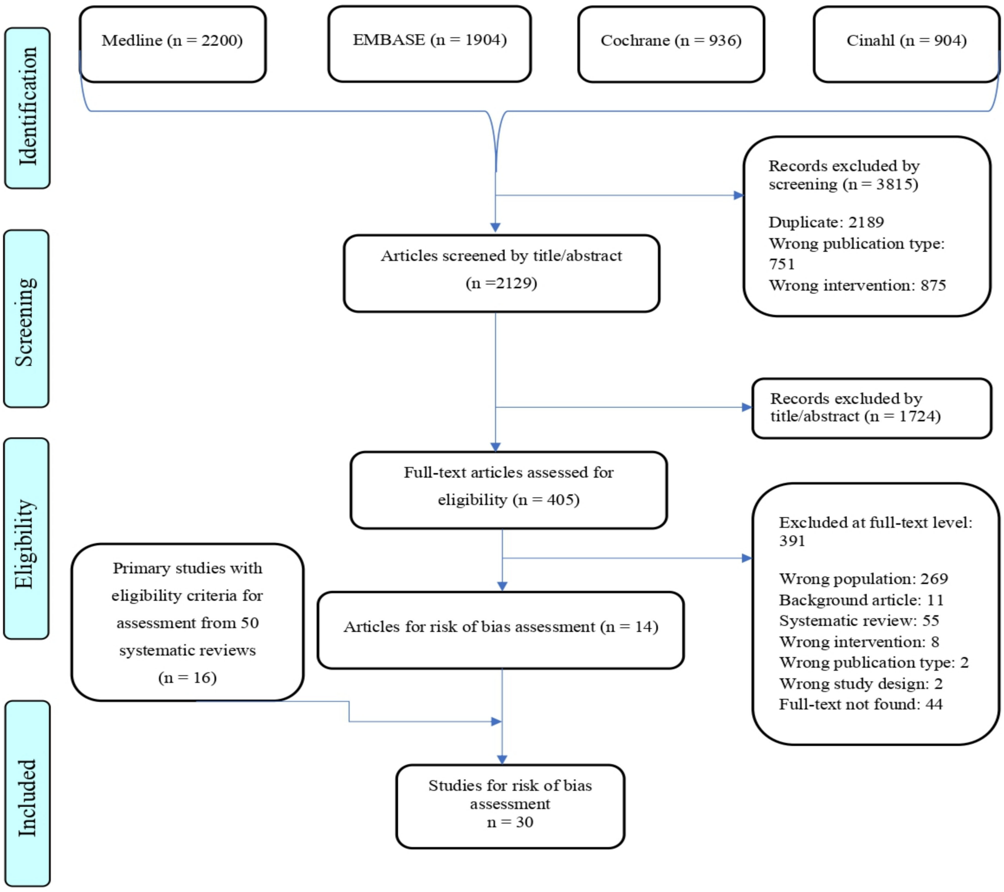


Figure 1. Study flow chart of studies evaluating clinical efficacy.

2.3.2. Data Extraction/Management

Data included author/s, publication year, design, sample and intervention characteristics, and outcomes. Funding information was from economic studies. Data extraction was performed in duplicate.

2.3.3. Risk-of-Bias Assessment

The Cochrane risk-of-bias 2 tool (RoB2) [15] was employed for clinical trials and the Risk-of-Bias in Non-randomized Studies of Interventions (Robins-I) [16] for cohort studies.

The Robins-I was adapted for quasi-experimental studies (Supplementary Material Table S2). Disease decline over time was assumed as a confounder and penalized if the participants were overstable/decompensated during follow-up. In the risk of bias due to intervention classification, intervention/inclusion criteria were either clearly predefined or not.

The Consensus Health Economic Criteria (CHEC) list was employed for economic evaluations [17].

All studies were peer-reviewed, and in the case of any discrepancies, consensus was reached. In studies that measured more than one outcome, these were assessed separately in the outcome domains of the tools.

2.3.4. Intervention Characteristics

Interventions were classified as basic or intensive and determined according to staff availability and issue management during follow-up. Table 1 depicts the intervention and characteristics.

Subgroup analyses were carried out by age ranges (>85 years, 65–85 years, <65 years) and time to follow-up (<6 months, 6–12 months, and >12 months). Population characteristics and outcome measurement instruments were evaluated.

Table 1. Characteristics and summary of results of the included studies for the evaluation of case management in advanced heart failure patients.

Studies Evaluating Clinical Efficacy								
Author, Year Country	**Study Design (Number of Subjects Included)**	**Mean Age (Standard Deviation) Case Management vs. Control**	**Gender (% Women) Case Management vs. Control**	**Population**	**Intervention Characteristics and Main Component ***	**Control**	**Maximum Follow-Up Time (Days)**	**Outcome Measures**
Aiken, 2006 [18] USA	RCT (N = 129)	68 (14) vs. 70 (13) $^{\beta}$	58 vs. 70	Patients from community or hospitalized with chronic heart failure in NYHA III or IV	Intensive intervention ^{b,f} Home visits	Usual care	270	Quality of life
Bondmass, 2007 [19] USA	RCT (N = 186)	62.1 (13.9) vs. 62.8 (12.4)	63.3 vs. 60.4	Patients hospitalized with HF in NYHA III or IV	Intensive intervention ^{c,f} Telemedicine	NHV: Nurse home visits	90	Treatment adherence, quality of life
Boyne, 2012 [20] Netherlands	RCT Total: (N = 382) Subgroup NYHA III: 153 Subgroup NYHA IV: 10	Total: 71.0 (11.9) vs. 71.9 (10.5) Subgroup in NYHA III and IV: not reported	Total: 42 vs. 40 Subgroup in NYHA III and IV: not reported	Patients in the community diagnosed with HF >18 years and being treated by an HF nurse and a cardiologist in an HF clinic Subgroup analysis in NYHA III and IV	Intensive intervention ^{a,c,e} Telemedicine	Usual Care	365	Hospitalizations for HF
Brännström, 2014 [21] Sweden	RCT (N = 72)	81.9 (7.2) vs. 76.6 (10.2)	27.8 vs. 30.6	Patients in the community diagnosed with HF in NYHA III or IV	Intensive intervention ^{b,f} Home visits	Usual Care	180	All-cause hospitalizations, quality of life, self-efficacy
Comin-Colet, 2016 [22] Spain	RCT (N = 178)	Total: 74 (11) vs. 75 (11) Subgroup in NYHA III and IV: not reported	Total: 43 vs. 39 Subgroup in NYHA III and IV: not reported	Patients hospitalized with HF Subgroup analysis in NYHA III and IV	Intensive intervention ^{c,d,f} Telemedicine	HF program	180	Hospitalizations for HF

Table 1. *Cont.*

Studies Evaluating Clinical Efficacy								
Author, Year Country	**Study Design (Number of Subjects Included)**	**Mean Age (Standard Deviation) Case Management vs. Control**	**Gender (% Women) Case Management vs. Control**	**Population**	**Intervention Characteristics and Main Component ***	**Control**	**Maximum Follow-Up Time (Days)**	**Outcome Measures**
De la Porte, 2007 [23] Netherlands	RCT (N = 340)	70 (10) vs. 71 (10)	34 vs. 21	Patients in the community or hospitalized with NYHA III or IV	Intensive intervention [a,f,g] Clinical consultations	Usual Care	365	All-cause mortality, hospitalizations for HF, self-care, and quality of life
Delaney, 2010 [24] USA	Quasi-experimental studio with control without randomization (N = 24)	Overall: 79.04 (11.8) $^{\pi}$	58.3 vs. 58.3	Patients with a primary diagnosis of HF in NYHA III or IV	Intensive intervention [b,c] Telemedicine	Usual care	90	Hospitalizations for HF, quality of life
Ekman, 1998 [25] Sweden	RCT (N = 158)	Overall: 80.3 (6.8) $^{\pi}$	42 $^{\pi}$	Patients hospitalized with HF in NYHA III or IV	Basic intervention [a,f,g] (office hours) Clinical consultations	Usual care	180	All-cause mortality, hospitalizations for HF, all-cause hospitalizations
Fonarow, 1997 [26] USA	Quasi-experimental pre-post (N = 214)	52.6 (10)	19	Patients in the community diagnosed with HF in NYHA III or IV and potential candidates for transplantation	Basic intervention [a,f] Clinical consultations	Usual care	180 pre and 180 post	All-cause mortality, hospitalizations for HF
GESICA, 2005 [27] Argentina	RCT Total: (N = 1518) Subgroup NYHA III or IV: (N = 750)	Total: 64.8 (13.9) vs. 65.2 (12.7) Subgroup: not reported	Total: 27.4 vs. 31.1 Subgroup in NYHA III and IV: not reported	Patients in the community diagnosed with HF and >18 years Subgroup analysis in NYHA III and IV	Basic intervention [f] Phone calls	Usual Care	From 180 to 365	Hospitalizations for HF

Table 1. *Cont.*

Studies Evaluating Clinical Efficacy								
Author, Year Country	**Study Design (Number of Subjects Included)**	**Mean Age (Standard Deviation) Case Management vs. Control**	**Gender (% Women) Case Management vs. Control**	**Population**	**Intervention Characteristics and Main Component ***	**Control**	**Maximum Follow-Up Time (Days)**	**Outcome Measures**
Goldberg, 2003 [28] USA	RCT (N = 280)	57.9 (15.7) vs. 60.2 (14.9)	30.4 vs. 34.5	Patients hospitalized with HF in NYHA III or IV	Intensive intervention [c] Telemedicine	Usual Care	180	All-cause mortality, hospitalizations for HF, all cause hospitalizations and quality of life
Holst, 2001 [29] Australia	Quasi-experimental (N = 42)	54 (13)	16.6	Patients with NYHA III or IV	Basic intervention [a] Clinic consultations	Usual care	180	All-cause hospitalizations, quality of life
Jaarsma, 1999 [30] Netherlands	RCT (N = 179)	73 (9) vs. 73 (9)	44 vs. 41	Patients hospitalized for HF with NYHA III or IV	Basic intervention [b,g] Home visits	Usual care	270	Hospitalizations for HF, All-cause hospitalizations, treatment adherence
Jaarsma, 2000 [31] Netherlands	RCT (N = 132)	72 (9) vs. 72 (10)	45 vs. 36	Patients admitted in cardiology unit for HF with NYHA III or IV	Basic intervention [a,b,f,g] Home visits	Usual care	270	Self-care, quality of life
Lynga, 2012 [13] Sweden	RCT (N = 319)	73.7 (9.9) vs. 73.5 (10.4)	24.1 vs. 26.1	Patients hospitalized for HF with NYHA III or IV	Basic intervention [a,c,g] Telemedicine	Usual Care	Up to cardiac hospitalization or 365 days	All-cause mortality, hospitalizations for HF, all-cause hospitalizations

Table 1. *Cont.*

Studies Evaluating Clinical Efficacy								
Author, Year Country	**Study Design (Number of Subjects Included)**	**Mean Age (Standard Deviation) Case Management vs. Control**	**Gender (% Women) Case Management vs. Control**	**Population**	**Intervention Characteristics and Main Component ***	**Control**	**Maximum Follow-Up Time (Days)**	**Outcome Measures**
Man, 2018 [32] China	RCT (N = 84)	78.3 (16.8) vs. 78.4 (10)	56.1 vs. 39	Patients hospitalized for HF with NYHA III or IV	Intensive intervention [b,f] Home visits	Usual care	90	Quality of life
McDonald, 2001 [33] Ireland	RCT (N = 70)	69.9 (11.3) vs. 67.9 (12)	14.3 vs. 18.6	Patients hospitalized with HF and NYHA III or IV	Basic intervention [a,f,g] Clinical consultations	Usual care	30	Hospitalizations for HF, all-cause mortality
Ong, 2016 [34] USA	RCT (N = 1437)	Median (interquartile range) Total: 73 (62–84) vs. 74 (63–82) Subgroup in NYHA III and IV: not reported	Total: 50.2 vs. 50.5 Subgroup in NYHA III and IV: not reported	Patients admitted to hospital for decompensated HF and >50 years old Subgroup analysis in NYHA III and IV	Intensive intervention [c,f,g] Telemedicine	Usual care	180	All-cause hospitalizations
Rogers, 2017 [12] USA	RCT (N = 150)	71.9 (12.4) vs. 69.8 (13.4)	44 vs. 50.7	Patients hospitalized for HF or within 2 weeks of discharge and dyspnea at rest or minimal exertion	Intensive intervention [b] Not clearly reported	Usual Care	180	All-cause mortality, hospitalizations for HF, all-cause hospitalizations, quality of life
Schellinger, 2011 [35] USA	Cohort study (N = 1894)	75.63 vs. 73.84 ∞	52 vs. 48.4 ∞	Patients with a primary or secondary HF diagnosis in community setting	Basic intervention [a] Clinical consultations	Usual care	60	All-cause hospitalizations

Table 1. *Cont.*

Studies Evaluating Clinical Efficacy								
Author, Year Country	**Study Design (Number of Subjects Included)**	**Mean Age (Standard Deviation) Case Management vs. Control**	**Gender (% Women) Case Management vs. Control**	**Population**	**Intervention Characteristics and Main Component ***	**Control**	**Maximum Follow-Up Time (Days)**	**Outcome Measures**
Shah, 1998 [36] USA	Quasi-experimental (N = 27) Subgroup NYHA III and IV (N = 17)	62 (range 42–81)	0	Patients hospitalized for HF	Basic intervention [f,g] Phone calls	Usual care	365	All-cause hospitalizations
Smith, 2014 [37] USA	RCT (N = 198)	62.6 (14.1) vs. 62.1 (12.5)	44 vs. 34	Patients hospitalized with HF in NYHA III or IV	Basic intervention [a] Clinical consultations	Usual Care	365	All-cause mortality, hospitalizations for HF
Vavouranakis, 2003 [38] Greece	Quasi-experimental (N = 33)	65.4 (6.7)	12.1	Patients in the community with HF and NYHA III or IV	Basic intervention [b,f,g] Home visits	Usual care	365	All-cause hospitalizations, quality of life
Yuet, 2016 [39] China	RCT (N = 84)	78.3 (16.8) vs. 78.4 (10.0)	55.1 vs. 39	Patients hospitalized with HF in NYHA III or IV	Intensive intervention [b,f] Home visits	Two placebo calls from assistant unrelated to clinical issues	90	All-cause hospitalizations, quality of life
Zamanzadeh, 2013 [40] Iran	RCT (N = 78)	65.82 (9.87) vs. 61.63 (12.47)	42.1 vs. 52.5	Patients diagnosed with HF in NYHA III or IV and an ejection fraction <40%	Basic intervention [a,f,g] Clinical consultations	Usual Care	90	Self-care (treatment adherence)

RCT: randomized control trial. HF: heart failure. NYHA: New York Heart Association. * This classification was based on the number of contacts made with the patients, staff availability, and the extent to which they addressed the issues during follow-up. The main component of each intervention was also described: [a]—clinical consultations, [b]—home visits, [c]—remote vital sign monitoring, [d]—videophone, [e]—messaging, [f]—scheduled telephone calls, [g]—telephone availability of staff (unscheduled). [∞] There is no exact information about the "no program" group but it seems to be similar to the uncompleted follow-up. [π] Case management vs. control not reported. [β] Population with advanced chronic diseases. Advanced HF disease not reported.

2.3.5. Data Synthesis and Registry

The analysis was an intention-to-treat approach, and all participants were included to reduce the potential selection bias.

Outcome data were evaluated at <6 months, 6–12 months, and >12 months follow-up when available.

Mortality/hospitalization were meta-analyzed using Review Manager (RevMan, version 5.3.5., Cochrane Collaboration, Oxford, UK) and STATA software (v.14.0, STATA Corp, College Station, TX, USA). Pooled relative risk ratios (RRs) and standard mean differences (SMDs) for binary and continuous outcomes were evaluated with the random effect model approach. When means and standard deviations (SDs), or changes of means and SDs from baseline were not reported, they were calculated using standard errors (SE), confidence intervals (CI), or the correlation coefficient.

Magnitude of heterogeneity was assessed using Higgins's I^2 statistics and interpreted according to the Cochrane Handbook (0–40%: low, 30–60%: moderate, 50–90%: substantial, 75–100%: considerable). Meta-analysis forest plots for consistency were inspected, given that I^2 statistics might be artificially inflated when effect estimates from primary studies were very precise [41].

For all meta-analyses with at least 10 included studies, the publication bias was assessed by a visual inspection of Begg's funnel plot and statistically, using Egger's test for small study effects (funnel plot asymmetry).

Systematic Reviews of Economic Evaluations guides were followed to analyzed costs and the cost-effectiveness of primary studies [42].

The study was registered in the International Prospective Register of Systematic Reviews (PROSPERO) and published with ID number CRD42020160810.

3. Results

3.1. Selection of Primary Studies

From 5944 records from four databases, 2129 studies remained. We then reviewed 405 full-text articles: 14 were selected for synthesis. We also reviewed all primary studies obtained from 55 systematic reviews identified in the title/abstract screening and selected 16. In total, 30 studies were included in the evidence synthesis. Of these 30, 25 described the benefits/risks of a nurse-led CM model, and 5 were economic evaluations (Figure 1).

3.2. Study Characteristics

3.2.1. Evidence of Effects (Benefits and Risks)

The 25 included studies were published between 1997 and 2016 (Table 1). The majority (17) were from the US and European countries. Most were randomized controlled trials, except for five quasi-experimental studies and one prospective cohort.

Populations were mainly men >60 years. The identification was performed primarily at the hospital or community level. In 22 of the 25 included studies, the comparator was usual care. Most studies had a follow-up of more than six months, with a maximum of one year.

Twelve intensive and thirteen basic programs compared their effect with usual care. The intensity classification was based on the number of contacts made with the patients, staff availability, and to what extent they addressed the issues in the follow-up visits. Telemedicine and home-visit interventions were mainly intensive programs whereas others (clinical consultations, phone calls) were basic.

3.2.2. Cost-Effectiveness Studies

Five economic evaluations were identified. Three were cost-effectiveness studies, and two cost-benefit analyses. All had been performed in high-income countries, four in European ones and another in the US (Table 2).

Table 2. Characteristics and summary of results of the included studies for the economic evaluation of case management in advanced heart failure patients.

Studies Evaluating the Economic Evidence for Nurse Case Management

Author, Year	Study Design, Country	Population	Intervention Characteristics *	Control	Time Horizon, Perspective	Difference in Cost (Year Value)	Difference in Outcome		ICER		Risk of Bias (CHEC Score)
Gregory, 2006 [43]	Cost-benefit, USA	Patients admitted to hospital with primary diagnosis of HF in NYHA III or IV	Intensive intervention: 2, 6, 7 (24 h availability)	SC	90 days, healthcare perspective	Reference SC: USD 3979 (2003) USA Dollars Intensive vs. SC: USD 996 additional cost per patient	USD −759 due to reduction in hospitalization costs per patient		USD +237 not considered cost saving		11.5/19
Ledwidge, 2003 [44]	Cost-benefit, Ireland	Patients admitted to hospital with a diagnosis of HF in NYHA IV	Basic intervention: 1, 6, 7 (working hours)	SC	3 months, healthcare perspective	Reference SC: no cost Basic vs. SC: EUR 113 (1999) additional cost per patient	EUR −43,955 due to reduction in hospitalization costs per patient		Net saving EUR −379.75 per patient		12/19
Postmus, 2011 [45]	Cost-effectiveness, Sweden	Patients admitted to hospital with primary diagnosis of HF in NYHA III or IV	Basic intervention: 1, 7 (working hours) Intensive intervention: 1, 2, 6, 7 (24 h availability)	SC	18 months, healthcare perspective	Reference SC: EUR 10,692 per patient (2009)	QALY	LY	QALY (cost/QALY)	LY (cost/LY)	14/19
						Basic vs. SC: EUR 1101 additional cost per patient (2009)	Basic vs. SC: 0.014	Basic vs. SC: 0.042	Basic vs. SC: EUR 77,335	Basic vs. SC: EUR 25,923	
						Intensive vs: SC: EUR 1770 additional cost per patient (2009)	Intensive vs. SC: 0.029	Intensive vs. SC: 0.057	Intensive vs. SC: EUR 59,289	Intensive vs. SC: EUR 30,933	
						Intensive vs. basic: EUR 669 additional cost per patient (2009)	Intensive vs. basic: 0.015	Intensive vs. basic: 0.014	Intensive vs. basic: EUR 42,839	Intensive vs. basic: EUR 45,219	

Table 2. *Cont.*

Studies Evaluating the Economic Evidence for Nurse Case Management											
Author, Year	**Study Design, Country**	**Population**	**Intervention Characteristics ***	**Control**	**Time Horizon, Perspective**	**Difference in Cost (Year Value)**	**Difference in Outcome**		**ICER**		**Risk of Bias (CHEC Score)**
Grustam, 2018 [46]	Cost-effectiveness Markov model, Netherlands	Patients > 70 years admitted to hospital with a diagnosis of HF in NYHA IV	Basic intervention (nurse telephone support): 1, 6, 7 (working hours) Intensive intervention (home telemonitoring): 3	SC	Lifetime (20 years), health system perspective	Reference SC: EUR 15,407 per patient (2015)	QALY	LY	QALY (cost/QALY)	LY (cost/LY)	16/19
						Basic vs. SC: EUR 7042 additional cost per patient (2015)	Basic vs. SC: 0.75	Basic vs. SC: 0.96	Basic vs. SC: EUR 9398	Basic vs. SC: EUR 7364	
						Intensive vs. SC: EUR 12,131 additional cost per patient (2015)	Intensive vs. SC: 0.86	Intensive vs. SC: 1.14	Intensive vs. SC: EUR 14,027	Intensive vs. SC: EUR 10,644	
						Intensive vs. basic: EUR 5090 additional cost per patient (2015)	Intensive vs. basic: 0.12	Intensive vs. basic: 0.18	Intensive vs. basic: EUR 44,040	Intensive vs. basic: EUR 27,733	
Sahlen, 2016 [47]	Cost-effectiveness, Sweden	Patients diagnosed with HF in NYHA III or IV and attended in the community	Intensive intervention: 2, 6	SC	6 months, healthcare perspective	Reference SC: EUR 5727 per patient (2012) Intensive vs. SC: EUR −1649 saving cost per patient	0.25 QALY		Dominant		13/19

* Intervention characteristics; ^{1}—clinical consultations, ^{2}—home visits, ^{3}—remote vital signs monitoring, ^{4}—videophone, ^{5}—messaging, ^{6}—scheduled telephone calls, ^{7}—telephone availability of staff (unscheduled). ICER: incremental cost-effectiveness ratio. QALY: quality-adjusted life years. LY: life year. CHEC: consensus on health economics criteria checklist. SC: standard care. HF: heart failure. NYHA: New York Heart Association.

3.3. Quality of Included Studies

3.3.1. Randomized Control Trials

The RoB2 Cochrane [15] tool was used to evaluate the risk of bias (Supplementary Material Table S3). Most studies presented issues with random sequence generation; however, baseline group characteristics did not suggest a randomization concern.

To evaluate the risk of bias of the reported results, all study original protocols were examined to compare the planned statistical analysis with the final result. In nine studies, the protocol was missing and thus referred to as a lack of information with some concerns. Most studies with protocol (8 out of 10) were assessed as a low risk of bias. Hospitalization/mortality was considered a low risk of bias. QoL and self-care outcomes presented some concerns as the interventions were not blinded, and the questionnaires were generally self-reported (Supplementary Material Table S3).

3.3.2. Nonrandomized Trials

The risk of bias in the quasi-experimental and cohort studies was assessed with the ROBINS-I tool (16) (Supplementary Material Table S4). Only one cohort study was identified (Schellinger 2011 [35]). Studies were classified as having a high risk of bias when patients were too stable/decompensated during follow-up. If no control group was present, the progression of advanced HF was considered to play a role in the intervention effectiveness.

Since nonrandomized control trials had lower levels of evidence than randomized ones, they were not included in the meta-analysis, although descriptively reported.

3.3.3. Economic Evaluations

The CHEC tool [17] was used to assess the economic evaluations (Table 2). All studies had a clear research question, with a well-defined population. The economic evaluations were considered as social ones, since they included costs related to patient care beyond hospital admissions. The quality of such studies was therefore downgraded.

Intervention cost-effectiveness was taken to be >6 months although three of the five studies had a shorter follow-up time. Only one study declared its source of funding (Sahlen et al. [47]).

Overall, three economic evaluations had a moderate/low risk of bias, and two were high risk.

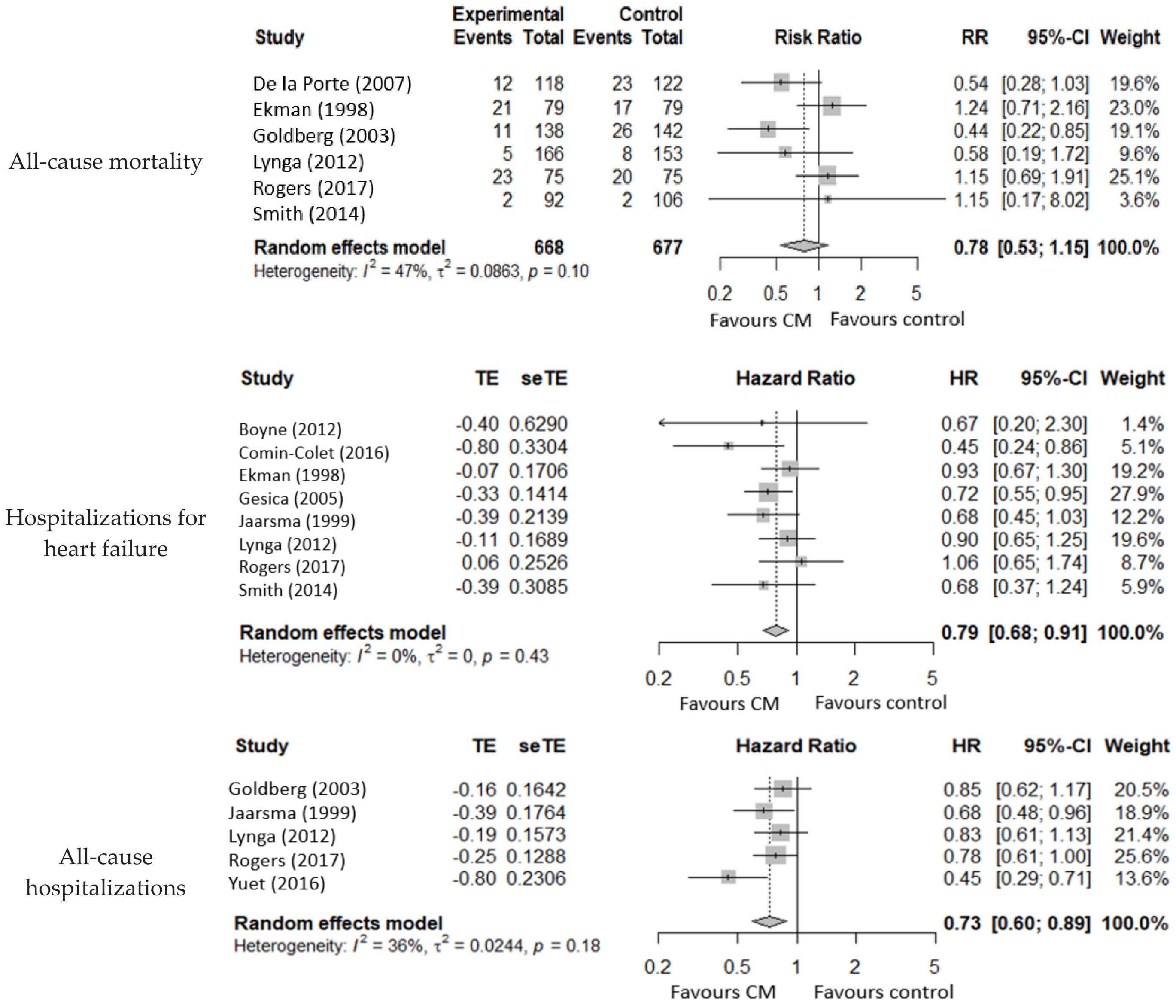
3.4. Evidence of Effects

3.4.1. All-Cause Mortality

Six studies reported all-cause mortality and indicated no improvement (RR 0.78, 95% CI 0.53 to 1.15; participants = 1345; studies = 6; I^2 = 47%, low risk of bias).

The follow-up was 12 months in three studies and 6 months in the others. To avoid one death, 32.15 patients were required (Figure 2).

The forest plot did not suggest a marked heterogeneity, nor did the subgroup analysis by length of follow-up indicate differences amongst subgroups (p = 0.34). There were, however, some differences in the type of CM (p = 0.07). Telemedicine was more effective than home visits (RR 0.47, 95% CI 0.27 to 0.83; participants = 2686 in two studies I^2 0%, low risk of bias) with 6 and 12 months of follow-up (Goldberg 2003 [28] and Lynga 2012 [13], respectively) (Supplementary Material Figure S1).



All-cause mortality

Study	Experimental Events	Experimental Total	Control Events	Control Total	RR	95%-CI	Weight
De la Porte (2007)	12	118	23	122	0.54	[0.28; 1.03]	19.6%
Ekman (1998)	21	79	17	79	1.24	[0.71; 2.16]	23.0%
Goldberg (2003)	11	138	26	142	0.44	[0.22; 0.85]	19.1%
Lynga (2012)	5	166	8	153	0.58	[0.19; 1.72]	9.6%
Rogers (2017)	23	75	20	75	1.15	[0.69; 1.91]	25.1%
Smith (2014)	2	92	2	106	1.15	[0.17; 8.02]	3.6%
Random effects model		**668**		**677**	**0.78**	**[0.53; 1.15]**	**100.0%**

Heterogeneity: $I^2 = 47\%$, $\tau^2 = 0.0863$, $p = 0.10$

Hospitalizations for heart failure

Study	TE	seTE	HR	95%-CI	Weight
Boyne (2012)	-0.40	0.6290	0.67	[0.20; 2.30]	1.4%
Comin-Colet (2016)	-0.80	0.3304	0.45	[0.24; 0.86]	5.1%
Ekman (1998)	-0.07	0.1706	0.93	[0.67; 1.30]	19.2%
Gesica (2005)	-0.33	0.1414	0.72	[0.55; 0.95]	27.9%
Jaarsma (1999)	-0.39	0.2139	0.68	[0.45; 1.03]	12.2%
Lynga (2012)	-0.11	0.1689	0.90	[0.65; 1.25]	19.6%
Rogers (2017)	0.06	0.2526	1.06	[0.65; 1.74]	8.7%
Smith (2014)	-0.39	0.3085	0.68	[0.37; 1.24]	5.9%
Random effects model			**0.79**	**[0.68; 0.91]**	**100.0%**

Heterogeneity: $I^2 = 0\%$, $\tau^2 = 0$, $p = 0.43$

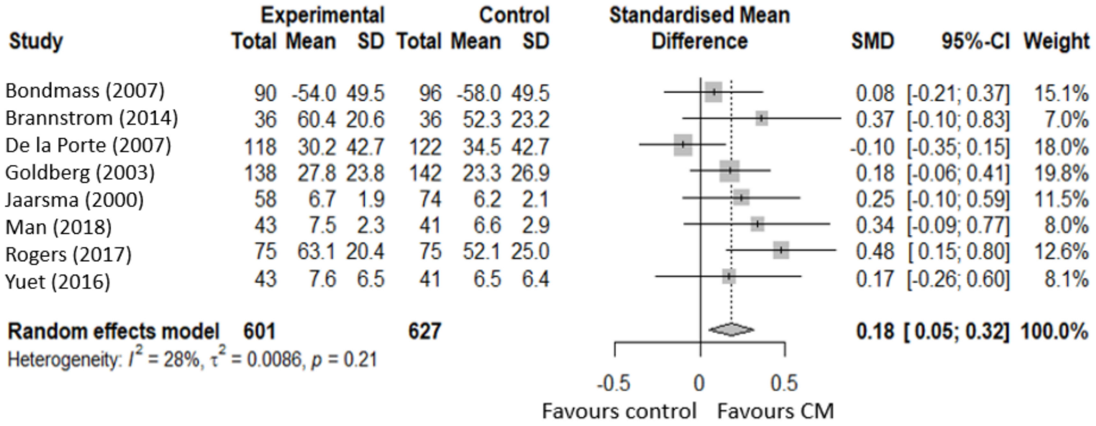
All-cause hospitalizations

Study	TE	seTE	HR	95%-CI	Weight
Goldberg (2003)	-0.16	0.1642	0.85	[0.62; 1.17]	20.5%
Jaarsma (1999)	-0.39	0.1764	0.68	[0.48; 0.96]	18.9%
Lynga (2012)	-0.19	0.1573	0.83	[0.61; 1.13]	21.4%
Rogers (2017)	-0.25	0.1288	0.78	[0.61; 1.00]	25.6%
Yuet (2016)	-0.80	0.2306	0.45	[0.29; 0.71]	13.6%
Random effects model			**0.73**	**[0.60; 0.89]**	**100.0%**

Heterogeneity: $I^2 = 36\%$, $\tau^2 = 0.0244$, $p = 0.18$

Figure 2. *Cont.*

Quality of life



Self-care

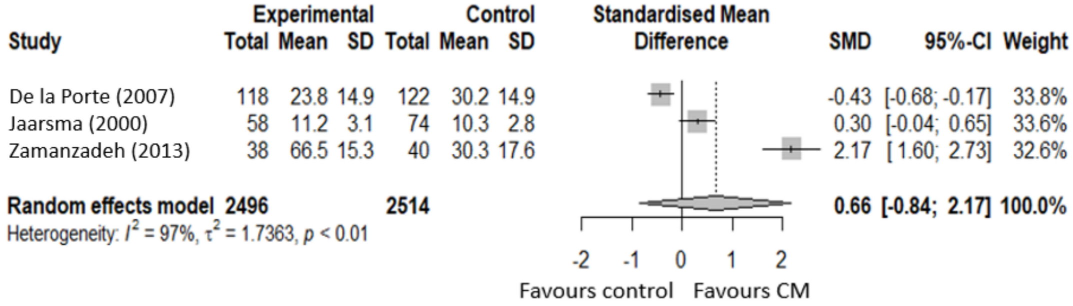


Figure 2. Metanalysis for all-cause mortality, hospitalizations for heart failure, all-cause hospitalizations, quality of life, and self-care. CM: nurse-led case management.

3.4.2. Mortality for Heart Failure

None of the studies reported deaths due to HF.

3.4.3. Hospitalizations for Heart Failure

Eight studies described HF hospitalizations and results showed CM as effective in avoiding them (HR 0.79, 95% CI 0.68 to 0.91; participants = 1989; studies = 8; I^2 = 0%, low risk of bias).

Five studies lacked full information, and two were not randomized controlled trials, and thus excluded. Nevertheless, the results showed that CM was beneficial for advanced HF (Supplementary Material Table S5).

3.4.4. All-Cause Hospitalizations

Five studies reported hospitalizations for all causes and demonstrated CM as protective for this outcome (HR 0.73, 95% CI 0.60 to 0.89; participants = 1012; studies = 5; I^2 = 36%, low risk of bias).

The subgroup analysis by age, time to follow-up, and CM type did not suggest any differences among groups (p = NA, p = 0.05 and p = 0.40, respectively) (Supplementary Material Figure S1).

Seven studies were excluded since four were not randomized controlled trials and three lacked information. Nevertheless, results indicated the benefits of nurse-led CM (Supplementary Material Table S5).

3.4.5. Quality of Life

Eight studies reported QoL and indicated a beneficial effect (SMD 0.18, 95% CI 0.05 to 0.32; participants = 1228; studies = 8; I^2 = 28%, moderate risk of bias) (Figure 2).

Subgroup differences in follow-up showed that the beneficial effect started at 6 months but was lost at 12 months (p = 0.02). In addition, testing for subgroup differences in the type of nurse-led CM suggested an improvement in home visits rather than telemedicine or other means (p = 0.02) (Supplementary Material Figure S1).

3.4.6. Self-Care

Three studies reported self-care and indicated a statistically nonsignificant beneficial effect. The heterogeneity among studies was high (SMD 0.66, 95% CI −0.84 to 2.17; participants = 450; studies = 3; I^2 = 97%, moderate risk-of-bias).

3.5. Costs and Cost-Effectiveness of Nurse-Led CM

3.5.1. Cost of the Intervention

Except for one study (Sahlen et al. [47]), all reported that investment in a new intervention was greater than in usual care. Cost varied according to intensity, year of implementation, and country. Related costs were mainly linked to healthcare professionals and telemedicine devices in those studies proposing remote data transfer (Table 2).

3.5.2. Cost-Effectiveness (Cost per QALY)

Three studies reported results in the incremental cost-effectiveness ratio (ICER) per QALY of the intervention compared with usual care. They also presented the lowest risk of bias and the largest time horizon (Postmus et al., Grustam et al. and Sahlen et al. [45–47]). They reported that intensive interventions, compared with basic ones/usual care, obtained larger benefits in terms of QALY and LY in NYHA III/IV patients. Regarding the ICER per QALY, ICERs of EUR 59,289 and EUR 14,027, respectively, were observed when comparing intensive versus usual care. Figures were below EUR 60,000/QALY.

3.5.3. Cost-Benefit Studies

Studies reported savings due to fewer hospital admissions. The net benefit was mainly determined by the price of the intervention.

4. Discussion

This systematic review summarized the quality of evidence regarding the effectiveness/cost-effectiveness of nurse-led CM programs in advanced HF populations. We included 30 studies, 25 reported effectiveness (19 randomized controlled trials, 5 quasi-experimental, and 1 cohort), and 5 economic evaluations. Only meta-analyzed studies with a low risk of bias, or with the lowest risk of bias available, were analyzed. Nonrandomized trials or studies lacking data were excluded. The latter were presented as narrative results and showed the same direction of effectiveness.

Our results were nonsignificant to indicate that nurse-led CM intervention reduced all-cause mortality. Interventions with telemedicine were the most effective. No study reported mortality due to HF.

Regarding HF hospitalizations, we found eight low-risk-of-bias randomized controlled trials. Five additional studies were narratively summarized. Nurse-led CM, telemedicine, and home visits were effective in preventing HF and all-cause hospitalizations.

Eight studies reported an improvement in QoL at 6 months which did not extend at 12 months. Three studies suggested that patients in the program had better self-care, although this was not statistically significant and the intervention costs among studies ranged from USD 4975 (2003-year value) to EUR 27,538 (2015-year value).

The most recent similar review (Takeda) explored different CM interventions for all-stage HF patients. Whilst our results concurred, they were not statistically significant, in contrast to other authors [11,48,49]; the fact that our population was at the final stage of the disease may have played a role.

In a similar manner to Bashi et al. [50], we found that patients with lower mortality were those who received telemedicine. Such results are, however, controversial as Flodgren et al. described no differences with usual care [51]. Reasons for this may include sociocultural differences, and in this sense, further research is required.

We observed that the nurse-led CM interventions reduced the risk of hospitalizations. This is a relevant finding since hospitalizations for advanced HF are common [52] and avoiding hospitalization can also reduce mortality [53].

In agreement with Rice et al. [54], QoL improved with the intervention. We found, however, that in our population this was at 6 months after the intervention and only lasted up to 12 months. Nevertheless, due to the advanced stage of the disease, we believe any gain, or even maintenance, in the QoL of patients with advanced HF to be relevant.

QoL did not improve in the telemedicine group, concurring with Bauce et al. [55]. Personal contact with healthcare professionals can produce a certain emotional proximity which may have a positive impact on QoL and should be further evaluated.

Nurse-led CM interventions could also improve self-care [56]. Nevertheless, our findings were not statistically significant, and there was considerable heterogeneity among studies. The intervention effect was lost with time as patients lost motivation. Factors favoring long-term self-care should be further explored as they have an impact on the reduction of hospital admissions [57].

Nurse-led CM could be cost-effective, a finding that concurs with Rice et al. [54], probably due to the savings from fewer hospitalizations. In terms of QALYs, Fergenbaum et al. concluded that a home-based intervention improved the QALY by 0.11 and reduced costs [58]. In our review, all the studies that reported QALYs described improvements above the figure described by Fergenbaum except for the Postmus study.

Advanced HF patients require more resources to improve their QALY thus increasing incremental cost. Nurse-led CM was not found to be particularly cost-effective, nevertheless, a threshold of EUR 60,000/QALY may be considered affordable for high-income countries.

Further studies should consider differentiating advanced HF from the general HF population, since this subgroup has different needs.

Limitations

- The limitations of this systematic review are mostly derived from those of the primary included studies. We found seven, five, and four studies corresponding to all-cause hospitalizations, HF hospitalizations, and QoL, respectively, with concerns of a high risk of bias leading to their exclusion from the pooled analysis. We did, however, narratively summarize these data and found similar results in most cases.
- Nurse-led CM interventions may have varying characteristics according to their settings which could result in heterogeneity. For clarification, we created a descriptive table with all the characteristics of each intervention.
- The CM overall effect can be affected over time. We observed a short-term beneficial effect that was depleted on the medium/long term. We therefore carried out the meta-analysis with different follow-up time groups to analyze this factor.

5. Conclusions

Nurse-led CM can reduce all-cause hospital admissions and HF hospitalizations but not all-cause mortality. QoL improved in medium-term follow-up, and better self-care/survival was reported, although it was not statistically significant. The intervention could be cost-effective for less than EUR 60,000/QALY. More intensive nurse-led case management studies are needed to determine the cost-effectiveness of the program.

Supplementary Materials: The following supporting information can be downloaded at: https://www.mdpi.com/article/10.3390/ijerph192113823/s1, Figure S1: Meta-analysis of subgroups according follow-up time, type of nurse-led case management delivered and age Table S1: Excluded articles at full text level; Table S2: ROBINS-I adaptation; Table S3: Assessment of Risk of bias (RoB) in Randomized controlled trial studies; Table S4: Assessment of Risk of bias with adaptation ROBINS-I tool in non-Randomized controlled trial studies; Table S5: Descriptive tables of studies with incomplete outcome data.

Author Contributions: Conceptualization, C.C. and M.P.; methodology, M.P., X.C. and C.C.; software, C.C.; validation, S.S., D.G.-L., A.B., X.C., C.B. and M.P.; formal analysis, C.C.-A., C.C. and M.P.; investigation, C.C., C.C.-A., S.S., D.G.-L., A.B., X.C., C.B. and M.P.; resources, C.C., C.C.-A., S.S., D.G.-L. and A.B.; data curation, C.C.-A.; writing—original draft preparation, C.C., M.P. and D.G.-L.; writing—review and editing, C.C., C.C.-A., S.S., D.G.-L., A.B., X.C., C.B. and M.P.; visualization C.C., C.C.-A., S.S., D.G.-L., A.B., X.C., C.B. and M.P.; supervision, M.P.; project administration, C.C. and M.P.; funding acquisition, C.C. All authors have read and agreed to the published version of the manuscript.

Funding: This study was developed with the support of the Departament de Salut de la Generalitat de Catalunya, in the call corresponding to 2018 for the granting of subsidies from the Pla Estratègic de Recerca i Innovació en Salut (PERIS) 2019–2021, modality of "Grants for the intensification of the research activity of health professionals without specialized health training", with the file code SLT008/18/00130. Webpage: http://salutweb.gencat.cat/ca/inici/, accessed on 20 October 2022.

Acknowledgments: We would like to thank Lorea Galnares Cordero, for her work in the strategy and search of primary studies for this review in the databases. Secondly, we thank Stephanie Lonsdale Anning for her review of the written English of this paper. This systematic review is part of the work of the Doctoral Program in Methodology of Biomedical Research and Public Health at the Department of Pediatrics, Obstetrics, and Gynecology, Preventive Medicine, and Public Health, Universitat Autònoma de Barcelona (UAB) in which the researcher, Caterina Checa, is studying.

Conflicts of Interest: The authors have declared that no competing interests exist. The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

Appendix A Electronic Database Strategy

Medline, Via Pubmed	
Heart Failure	
#1	Search "Heart Failure"[Mesh]
#2	Search "Heart Arrest"[Mesh]
#3	Search "Shock, Cardiogenic"[Mesh]
#4	Search (heart[Title/Abstract] OR cardi *[Title/Abstract] OR myocard *[Title/Abstract]) AND (failur *[Title/Abstract] OR decompensat *[Title/Abstract] OR insufficien *[Title/Abstract] OR incompet *[Title/Abstract] OR arrest[Title/Abstract] OR shock[Title/Abstract])
#5	Search #1 OR #2 OR #3 OR #4 344766
Nurses	
#6	Search "Nurses"[Mesh]
#7	Search "Nurses, Community Health"[Mesh]
#8	Search "Nursing"[Mesh]
#9	Search "Primary Nursing"[Mesh]
#10	Search "Nursing Care"[Mesh]
#11	Search "Primary Care Nursing"[Mesh]
#12	Search "Practice Patterns, Nurses"[Mesh]
#13	Search nurs *[Title/Abstract]
#14	Search "Patient Care Team"[Mesh]
#15	Search (multidisciplinar *[Title/Abstract] OR multi-disciplinar *[Title/Abstract] OR interdisciplinar *[Title/Abstract]) OR ((care[Title/Abstract] OR healthcare[Title/Abstract] OR "health care")[Title/Abstract] AND (team[Title/Abstract] OR teams[Title/Abstract]))
#16	Search #6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15 754499

Case Management	
#17	Search "Patient Care Management"[Mesh]
#18	Search "Patient Care Planning"[Mesh]
#19	Search "Case Management"[Mesh]
#20	Search "Case Managers"[Mesh]
#21	Search "Disease Management"[Mesh]
#22	Search manag *[Title/Abstract]
#23	Search #17 OR #18 OR #19 OR #20 OR #21 OR 1893972
Primary Care	
#24	Search "Primary Health Care"[Mesh]
#25	Search "General Practice"[Mesh]
#26	Search "Family Practice"[Mesh]
#27	Search "Community Medicine"[Mesh]
#28	Search "Community Health Services"[Mesh]
#29	Search "Community Health Nursing"[Mesh]
#30	Search "Home Care Services"[Mesh]
#31	Search "Home Health Nursing"[Mesh]
#32	Search "Community Health Planning"[Mesh]
#33	Search "Community Health Centers"[Mesh]
#34	Search "Ambulatory Care"[Mesh]
#35	Search "Ambulatory Care Facilities"[Mesh]
#36	Search (primary[Title/Abstract]) AND (care[Title/Abstract] OR healthcare[Title/Abstract] OR "health care"[Title/Abstract])
#37	Search ((general[Title/Abstract] OR family[Title/Abstract])) AND (practic *[Title/Abstract] OR medicine[Title/Abstract])
#38	Search (community[Title/Abstract]) AND (medicine[Title/Abstract] OR care[Title/Abstract] OR healthcare[Title/Abstract] OR service[Title/Abstract] OR services[Title/Abstract] OR health[Title/Abstract])
#39	Search ((ambulatory[Title/Abstract] OR outpatient[Title/Abstract])) AND care[Title/Abstract]
#40	Search ((community[Title/Abstract] OR neighbo*[Title/Abstract] OR outpatient[Title/Abstract] OR walk-in[Title/Abstract] OR "walk in"[Title/Abstract])) AND (center[Title/Abstract] OR centers[Title/Abstract] OR centre[Title/Abstract] OR centres[Title/Abstract] OR clinic[Title/Abstract] OR clinics[Title/Abstract])
#41	Search (home[Title/Abstract]) AND (care[Title/Abstract] OR health[Title/Abstract])
#42	Search #24 OR #25 OR #26 OR #27 OR #28 OR #29 OR #30 OR #31 OR #32 OR #33 OR #34 OR #35 OR #36 OR #37 OR #38 OR #39 OR #40 OR #41 1133580
TOTAL	
#43	Search #5 AND #16 AND #23 AND #42 2055

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Table S1. Excluded articles at full text level

Title	Year	Journal	Volume	Issue	Pages	Authors	Exclusion Reasons
Risk score-guided multidisciplinary team-based Care for Heart Failure Inpatients is associated with lower 30-day readmission and lower 30-day mortality	2019	Am Heart J	219		78-88	Horne,B.D et al	wrong population
Nurse-Led Collaborative Management Using Telemonitoring Improves Quality of Life and Prevention of Rehospitalization in Patients with Heart Failure	2019	Int Heart J	60	6	1293-1302	Mizukawa,M et al	wrong population
Implementation and Impact of Home-Based Cardiac Rehabilitation in a Veterans Affair Medical Center	2019	Mil Med	185	44352	e859-e863	Prasada,S et al	wrong population
Implementation of a Shared Medical Appointment as a Holistic Approach to CHF Management	2019	Holist Nurs Pract	33	6	354-359	Law,T et al	wrong population
The development and pilot study of a nurse-led HOMe-based HEart failure self-Management Programme (the HOM-HEMP) for patients with chronic heart failure, following Medical Research Council guidelines	2019	Eur J Cardiovasc Nurs	19	3	212-222	Jiang,Y et al	wrong population
Value of information analysis in telehealth for chronic heart failure management	2019	PLoS One	14	6	e0218083	Grustam,A.S et al	wrong population
Coordinated-Transitional Care for Veterans with Heart Failure and Chronic Lung Disease	2019	J Am Geriatr Soc	67	7	1502-1507	Reese,R.L et al	wrong population
Implementation of an intensified outpatient follow-up protocol improves outcomes in patients with ventricular assist devices	2019	Clin Res Cardiol	108	11	1197-1207	Hamed,S et al	wrong intervention
Effect of Patient-Centered Transitional Care Services on Clinical Outcomes in Patients Hospitalized for Heart Failure: The PACT-HF Randomized Clinical Trial	2019	JAMA	321	8	753-761	Van Spall,H.G.C et al	wrong population

Implications of Transitional Care Interventions on Hospital Readmissions in Patients With Destination Therapy Left Ventricular Assist Devices	2019	Res Theory Nurs Pract	33	1	81-96	Iseler,J.I et al	not found
Influence of Risk on Reduction of Readmission and Death by Disease Management Programs in Heart Failure	2019	J Card Fail	25	5	330-339	Huynh,Q.L et al	wrong population
Disease management interventions for heart failure	2019	Cochrane Database Syst Rev	1	1	CD002752	Takeda,A et al	systematic review
Effectiveness of a community care management program for multimorbid elderly patients with heart failure in the Veneto Region	2019	Aging Clin Exp Res	31	2	241-247	Tiozzo,S.N et al	wrong population
Effectiveness of the European Society of Cardiology/Heart Failure Association website 'heartfailurematters.org' and an e-health adjusted care pathway in patients with stable heart failure: results of the 'e-Vita HF' randomized controlled trial	2019	Eur J Heart Fail	21	2	238-246	Wagenaar,K.P et al	wrong population
Destination Therapy: Standardizing the Role of Palliative Medicine and Delineating the DT-LVAD Journey	2019	J Pain Symptom Manage	57	2	330-340	Woodburn,J.L et al	wrong intervention
A complex intervention of self-management for patients with COPD or CHF in primary care improved performance and satisfaction with regard to own selected activities; A longitudinal follow-up	2019	J Adv Nurs	75	1	175-186	Zakrisson,A.B et al	wrong population
Introducing nurse-led heart failure clinics in Swedish primary care settings	2019	Eur J Heart Fail	21	1	103-109	Liljeroos,M et al	wrong population
Evaluation of a nurse-led intervention program in heart failure: A randomized trial	2019	Med Clin (Barc)	152	11	431-437	Ortiz-Bautista,C et al	wrong population
The Effect of a Telephone-Based Self-management Program Led by Nurses on Self-care Behavior, Biological Index for Cardiac Function, and Depression in Ambulatory Heart Failure Patients	2018	Asian Nurs Res (Korean Soc Nurs Sci)	12	4	251-257	Moon,M.K et al	wrong population

Impact of telemedicine on the clinical outcomes and healthcare costs of patients with chronic heart failure and mid-range or preserved ejection fraction managed in a multidisciplinary chronic heart failure programme: A sub-analysis of the iCOR randomized trial	2020	J Telemed Telecare	24	1_2	65-72	Jimenez-Marrero,S et al	wrong population
Effects of a person-centred telephone-support in patients with chronic obstructive pulmonary disease and/or chronic heart failure - A randomized controlled trial	2018	PLoS One	13	8	e0203031	Fors,A et al	wrong population
Achieving IHI's Triple Aim by Utilizing Core Health Program With Community Health Workers in Rural Communities	2018	Fam Community Health	41	4	255-264	Fawcett,K.J.,Jr et al	wrong population
Effects of a multidisciplinary disease management programme with or without exercise training for heart failure patients: Secondary analysis of a randomized controlled trial	2018	Int J Nurs Stud	87		94-102	Liu,M.H et al	wrong population
Impact of the Implementation of Project Re-Engineered Discharge for Heart Failure patients at a Veterans Affairs Hospital at the Central Arkansas Veterans Healthcare System	2018	Hosp Pharm	53	4	266-271	Patel,P.H et al	wrong population
Heart Failure Management in Nursing Homes: A Scoping Literature Review	2018	Can J Cardiol	34	7	871-880	Heckman,G.A et al	systematic review
A review of integrated heart failure care	2018	Prim Health Care Res Dev	20		e57	MacInnes,J et al	systematic review
Opposite trends in hospitalization and mortality after implementation of a chronic care model-based regional program for the management of patients with heart failure in primary care	2018	BMC Health Serv Res	18	1	388	Ballo,P et al	wrong population
Effectiveness of a transition plan at discharge of patients hospitalized with heart failure: a before-and-after study	2018	ESC Heart Fail	5	4	657-667	Garnier,A et al	wrong population

Cost-Effectiveness of a Home Visit Program for Patients with Heart Failure in Brazil: Evidence from a Randomized Clinical Trial	2018	Value Health Reg Issues	17		81-87	Ruschel,K.B et al	wrong population
Effect of Grand-Aides Nurse Extenders on Readmissions and Emergency Department Visits in Medicare Patients With Heart Failure	2018	Am J Cardiol	121	11	1336-1342	Thomas,S.C et al	wrong population
Performance Improvement to Decrease Readmission Rates for Patients With a Left Ventricular Assist Device	2018	Prog Transplant	28	2	184-188	Iseler,J et al	wrong population
[Efficacy of a multidisciplinary care management program for patients admitted at hospital because of heart failure (ProMIC)]	2019	Aten Primaria	51	3	142-152	Domingo,C et al	wrong population
Effect of a Collaborative Care Intervention vs Usual Care on Health Status of Patients With Chronic Heart Failure: The CASA Randomized Clinical Trial	2018	JAMA Intern Med	178	4	511-519	Bekelman,D.B et al	wrong population
The first multicenter, randomized, controlled trial of home telemonitoring for Japanese patients with heart failure: home telemonitoring study for patients with heart failure (HOMES-HF)	2018	Heart Vessels	33	8	866-876	Kotooka,N et al	wrong population
Videoconferencing for Management of Heart Failure: An Integrative Review	2018	J Gerontol Nurs	44	4	45-52	Bauce,K et al	systematic review
Pilot testing of the effectiveness of nurse-guided, patient-centered heart failure education for older adults	2018	Geriatr Nurs	39	4	376-381	Mathew,S et al	wrong population
The effect of nurse-led education on hospitalisation, readmission, quality of life and cost in adults with heart failure. A systematic review	2018	Patient Educ Couns	101	3	363-374	Rice,H et al	systematic review
Home-based telerehabilitation in older patients with chronic obstructive pulmonary disease and heart failure: a randomised controlled trial	2018	Age Ageing	47	1	82-88	Bernocchi,P et al	wrong population
Palliative Care in Heart Failure: Rationale, Evidence, and Future Priorities	2017	J Am Coll Cardiol	70	15	1919-1930	Kavalieratos,D et al	systematic review

Telemanagement of Heart Failure Patients Across the Post-Acute Care Continuum	2018	Telemed J E Health	24	5	360-366	Dadosky,A et al	wrong population
Processes and Outcomes of Congestive Heart Failure Care by Different Types of Primary Care Models	2018	J Card Fail	24	1	9-18	Kuo,Y.F et al	wrong population
An evaluation of involving family caregivers in the self-care of heart failure patients on hospital readmission: Randomised controlled trial (the FAMILY study)	2017	Int J Nurs Stud	75		101-111	Deek,H et al	wrong population
Implementation of a Patient Navigator Program to Reduce 30-day Heart Failure Readmission Rate	2017	Prog Cardiovasc Dis	60	2	259-266	Di Palo,K.E et al	wrong population
Effect of Early Follow-Up After Hospital Discharge on Outcomes in Patients With Heart Failure or Chronic Obstructive Pulmonary Disease: A Systematic Review	2017	Ont Health Technol Assess Ser	17	8	1-37	Song, J et al	wrong population
Impact of a Multidisciplinary Heart Failure Postdischarge Management Clinic on Medication Adherence	2017	Clin Ther	39	6	1200-1209	Lu, L et al	wrong population
Standard vs. intensified management of heart failure to reduce healthcare costs: results of a multicentre, randomized controlled trial	2017	Eur Heart J	38	30	2340-2348	Scuffham,P.A et al	wrong population
Disease management in the treatment of patients with chronic heart failure who have universal access to health care: a randomized controlled trial	2017	BMC Med	15	1	90	Kalter-Leibovici,O et al	wrong population
[The APULIA HF multicenter study: efficacy of a management protocol shared between hospital and territorial health services for acute decompensated heart failure patients]	2017	G Ital Cardiol (Rome)	18	2	150-158	Iacoviello,M et al	wrong population
Transitional care interventions: Relevance for nursing in the community	2017	Public Health Nurs	34	5	454-460	Coffey,A et al	wrong population
The effectiveness of telemedicine in the management of chronic heart disease - a systematic review	2017	JRSM Open	8	3	2054270416681747	Kruse,C.S et al	systematic review

Comparative effectiveness of transitional care services in patients discharged from the hospital with heart failure: a systematic review and network meta-analysis	2017	Eur J Heart Fail	19	11	1427-1443	Van Spall,H.G.C et al	systematic review
Cost-effectiveness analysis for a tele-based health coaching program for chronic disease in primary care	2017	BMC Health Serv Res	17	1	138	Oksman,E et al	wrong population
Remote Monitoring of Patients With Heart Failure: An Overview of Systematic Reviews	2017	J Med Internet Res	19	1	e18	Bashi,N et al	systematic review
[Development and Effects of a Heart Health Diary for Self-Care Enhancement of Patients with Heart Failure]	2016	J Korean Acad Nurs	46	6	881-893	Shim,J.L et al	wrong intervention
Improving quality of life and decreasing readmissions in heart failure patients in a multidisciplinary transition-to-care clinic	2017	Heart Lung	46	2	79-84	Whitaker-Brown,C.D et al	wrong population
A Retrospective Comparison of Home Telehealth and Nursing Care With or Without Rehabilitation Therapy on Rehospitalization Rates of Individuals With Heart Failure	2017	J Cardiopulm Rehabil Prev	37	3	207-213	Martin,S et al	wrong population
What is the impact of systems of care for heart failure on patients diagnosed with heart failure: a systematic review	2016	BMC Cardiovasc Disord	16	1	195	Driscoll,A et al	systematic review
The Intensity of Primary Care for Heart Failure Patients: A Determinant of Readmissions? The CarPaths Study: A French Region-Wide Analysis	2016	PLoS One	11	10	e0163268	Duflos,C.M et al	wrong population
[Reduction of rehospitalisation on elderly heart failure patients: A retrospective cohort VISage network]	2016	Ann Cardiol Angeiol (Paris)	65	5	293-298	Labranche,D et al	wrong population
Feasibility study of a nurse-led heart failure education program	2016	Contemp Nurse	52	4	499-510	Baptiste,D.L et al	wrong population
Reducing Readmissions among Heart Failure Patients Discharged to Home Health Care:	2017	Health Serv Res	52	4	1445-1472	Murtaugh,C.M et al	wrong population

Effectiveness of Early and Intensive Nursing Services and Early Physician Follow-Up							
The E-Coach technology-assisted care transition system: a pragmatic randomized trial	2016	Transl Behav Med	6	3	428-437	Ritchie,C.S et al	wrong population
A High-Touch Model of Community-Based Specialist Palliative Care: Latent Class Analysis Identifies Distinct Patient Subgroups	2016	J Pain Symptom Manage	52	2	178-186	Dhingra,L et al	wrong study design
Does case management for patients with heart failure based in the community reduce unplanned hospital admissions? A systematic review and meta-analysis	2016	BMJ Open	6	5	e010933	Huntley,A.L et al	systematic review
Health-Related Quality of Life in Heart Failure Patients With Varying Levels of Health Literacy Receiving Telemedicine and Standardized Education	2016	Home Healthc Now	34	5	267-272	Yehle,K.S et al	wrong population
Evaluation of the efficacy of a nurse practitioner-led home-based congestive heart failure clinical pathway	2016	Home Health Care Serv	35	1	39-51	Moore,J.A	wrong population
Effects of a transitional palliative care model on patients with end-stage heart failure: a randomised controlled trial	2016	Heart	102	14	1100-1108	Wong,F.K et al	wrong population
Evaluation of a Community Health Service Center-Based Intervention Program for Managing Chronic Heart Failure	2016	Balkan Med J	33	1	45-51	Gu,M et al	wrong population
Decreasing Congestive Heart Failure Readmission Rates Within 30 Days at the Tampa VA	2016	Nurs Adm Q	40	2	146-152	Messina,W	wrong population
How effective is an in-hospital heart failure self-care program in a Japanese setting? Lessons from a randomized controlled pilot study	2016	Patient Prefer Adherence	10		171-181	Kato,N.P et al	wrong population
Nurse Practitioner Care Model: Meeting the Health Care Challenges With a Collaborative Team	2015	Nurs Econ	33	6	297-304	Kutzleb,J et al	not found
A systematic review of transitional-care strategies to reduce rehospitalization in patients with heart failure	2016	Heart Lung	45	2	100-113	Albert,N.M.	systematic review

Protocol-Driven Allied Health Post-Discharge Transition Clinic to Reduce Hospital Readmissions in Heart Failure	2015	J Am Heart Assoc	4	12		Donaho,E.K et al	wrong population
Impact of APN Home Visits in Reducing Healthcare Costs and Improving Function in Homebound Heart Failure	2015	Home Healthc Now	33	10	532-537	Echeverry,L.M et al	wrong population
Effectiveness of an interactive platform, and the ESC/HFA heartfailurematters.org website in patients with heart failure: design of the multicentre randomized e-Vita heart failure trial	2015	Eur J Heart Fail	17	12	1310-1316	Wagenaar,K.P et al	wrong population
Combining training in knowledge translation with quality improvement reduced 30-day heart failure readmissions in a community hospital: a case study	2016	J Eval Clin Pract	22	2	171-179	Wyer,P et al	wrong population
Interactive telemedicine: effects on professional practice and health care outcomes	2015	Cochrane Database Syst Rev		9	CD002098	Flodgren,G et al	systematic review
Evaluation of telehealth service for patients with congestive heart failure in the north of Israel	2016	Eur J Cardiovasc Nurs	15	3	e78-e84	Eilat-Tsanani,S et al	wrong population
Cost-effectiveness of home versus clinic-based management of chronic heart failure: Extended follow-up of a pragmatic, multicentre randomized trial cohort - The WHICH? study (Which Heart Failure Intervention Is Most Cost-Effective & Consumer Friendly in Reducing Hospital Care)	2015	Int J Cardiol	201		368-375	Maru,S et al	wrong population
Effect of Nurse-Implemented Transitional Care for Chinese Individuals with Chronic Heart Failure in Hong Kong: A Randomized Controlled Trial	2015	J Am Geriatr Soc	63	8	1583-1593	Yu,D.S et al	wrong population
Impact of a Multidisciplinary Heart Failure Post-hospitalization Program on Heart Failure Readmission Rates	2015	Ann Pharmacother	49	11	1189-1196	Jackevicius,C.A et al	wrong population
The clinical effectiveness and cost-effectiveness of clinical nurse specialist-led hospital to home transitional care: a systematic review	2015	J Eval Clin Pract	21	5	763-781	Bryant-Lukosius,D et al	systematic review

Outcome of Patients Discharged From a Heart Failure Disease Management Program following Their Clinical and Echocardiographic Recovery	2015	Cardiology	131	3	197-202	Proctor,P et al	wrong population
Heart failure remote monitoring: evidence from the retrospective evaluation of a real-world remote monitoring program	2015	J Med Internet Res	17	4	e101	Agboola,S et al	wrong population
Seamless Transitions: Achieving Patient Safety Through Communication and Collaboration	2018	J Patient Saf	14	1	e3-e5	Radhakrishnan,K et al	wrong population
Nurse-Led Multidisciplinary Heart Failure Group Clinic Appointments: Methods, Materials, and Outcomes Used in the Clinical Trial	2015	J Cardiovasc Nurs	30	4	S25-S34	Smith,C.E et al	wrong population
Telecare for diabetes, CHF or COPD: effect on quality of life, hospital use and costs. A randomised controlled trial and qualitative evaluation	2015	PLoS One	10	3	e0116188	Kenealy,T.W et al	wrong population
If home telemonitoring reduces mortality in heart failure, is this just due to better guideline-based treatment?	2015	J Telemed Telecare	21	6	331-339	Dierckx,R et al	wrong population
Care in the Home for the Management of Chronic Heart Failure: Systematic Review and Cost-Effectiveness Analysis	2015	J Cardiovasc Nurs	30	4	S44-S51	Fergenbaum,J et al	systematic review
Home telehealth and hospital readmissions: a retrospective OASIS-C data analysis	2015	Home Healthc Now	33	1	20-26	Thomason,T.R et al	wrong population
A heart failure initiative to reduce the length of stay and readmission rates	2014	Prof Case Manag	19	6	276-284	White,S.M et al	wrong population
Resource use and cost implications of implementing a heart failure program for patients with systolic heart failure in Swedish primary health care	2014	Int J Cardiol	176	3	731-738	Agvall,B et al	wrong population
A nurse-based strategy reduces heart failure morbidity in patients admitted for acute decompensated heart failure in Brazil: the HELEN-II clinical trial	2014	Eur J Heart Fail	16	9	1002-1008	de Souza,E.N et al	wrong population

[Early implementation of home care and 30 day readmissions in >65 years Veneto region patients discharged for heart failure and with disability]	2014	Assist Inferm Ric	33	2	67-73	Gennaro,N et al	not found
Transitional care interventions to prevent readmissions for persons with heart failure: a systematic review and meta-analysis	2014	Ann Intern Med	160	11	774-784	Feltner,C et al	systematic review
Efficacy of an integrated hospital-primary care program for heart failure: a population-based analysis of 56,742 patients	2014	Rev Esp Cardiol (Engl Ed)	67	4	283-293	Comin-Colet,J et al	wrong population
The effect of a randomized trial of home telemonitoring on medical costs, 30-day readmissions, mortality, and health-related quality of life in a cohort of community-dwelling heart failure patients	2014	J Card Fail	20	7	513-521	Blum,K et al	wrong population
The comparison of the effects of education provided by nurses on the quality of life in patients with congestive heart failure (CHF) in usual and home-visit cares in Iran	2014	Glob J Health Sci	6	3	256-260	Mehralian,H et al	wrong population
Integrated telehealth care for chronic illness and depression in geriatric home care patients: the Integrated Telehealth Education and Activation of Mood (I-TEAM) study	2014	J Am Geriatr Soc	62	5	889-895	Gellis,Z.D et al	wrong population
Cost-effectiveness of a nurse facilitated, cognitive behavioural self-management programme compared with usual care using a CBT manual alone for patients with heart failure: secondary analysis of data from the SEMAPHFOR trial	2014	Int J Nurs Stud	51	9	1214-1220	Mejia,A et al	wrong population
The effect of multidisciplinary heart failure clinic characteristics on 1-year postdischarge health care costs: a population-based study	2014	Med Care	52	3	272-279	Wijeysundera,H.C et al	wrong population

Nurse facilitated Self-management support for people with heart failure and their family carers (SEMAPHFOR): a randomised controlled trial	2014	Int J Nurs Stud	51	9	1207-1213	Cockayne,S et al	wrong population
Examining the effects of remote monitoring systems on activation, self-care, and quality of life in older patients with chronic heart failure	2015	J Cardiovasc Nurs	30	1	51-57	Evangelista,L.S et al	wrong population
Feasibility and acceptability of a collaborative care intervention to improve symptoms and quality of life in chronic heart failure: mixed methods pilot trial	2014	J Palliat Med	17	2	145-151	Bekelman,D.B et al	wrong population
Home-based telesurveillance program in chronic heart failure: effects on clinical status and implications for 1-year prognosis	2013	Telemed J E Health	19	8	605-612	Giordano,A et al	wrong population
The effect of telemonitoring at home on quality of life and self-care behaviors of patients with heart failure	2013	Home Healthc Nurse	31	7	368-377	Hoban,M.B et al	wrong population
Impact of telemonitoring home care patients with heart failure or chronic lung disease from primary care on healthcare resource use (the TELBIL study randomised controlled trial)	2013	BMC Health Serv Res	13		118	Martin-Lesende,I et al	wrong population
Transitional care programs improve outcomes for heart failure patients: an integrative review	2014	J Cardiovasc Nurs	29	2	140-154	Stamp,K.D et al	systematic review
Cost-utility analysis of nt-probnp-guided multidisciplinary care in chronic heart failure	2013	Int J Technol Assess Health Care	29	1	3-11	Moertl,D et al	wrong population
A population-based study to evaluate the effectiveness of multidisciplinary heart failure clinics and identify important service components	2013	Circ Heart Fail	6	1	68-75	Wijeysundera,H.C et al	wrong population
The benefits of using a heart failure management programme in Swedish primary healthcare	2013	Eur J Heart Fail	15	2	228-236	Agvall,B et al	wrong population
Telephone support to rural and remote patients with heart failure: the Chronic Heart Failure Assessment by Telephone (CHAT) study	2013	Cardiovasc Ther	31	4	230-237	Krum,H et al	wrong population
Impact of home versus clinic-based management of chronic heart failure: the WHICH? (Which Heart	2012	J Am Coll Cardiol	60	14	1239-1248	Stewart,S et al	wrong population

Failure Intervention Is Most Cost-Effective & Consumer Friendly in Reducing Hospital Care) multicenter, randomized trial							
A critical review on telemonitoring in heart failure	2012	Acta Cardiol	67	4	439-444	Gurne,O et al	systematic review
Clinical service organisation for heart failure	2012	Cochrane Database Syst Rev		9	CD002752	Takeda,A et al	systematic review
Role of a multidisciplinary program in improving outcomes in cognitively impaired heart failure older patients	2012	Monaldi Arch Chest Dis	78	1	20-28	Del,Sindaco D et al	wrong intervention
A systematic review of economic evaluations of cardiac rehabilitation	2012	BMC Health Serv Res	12		243	Wong,W.P et al	systematic review
Effect of a community-based nursing intervention on mortality in chronically ill older adults: a randomized controlled trial	2012	PLoS Med	9	7	e1001265	Coburn,K.D et al	wrong population
The impact of remote patient monitoring (telehealth) upon Medicare beneficiaries with heart failure	2012	Telemed J E Health	18	2	101-108	Pekmezaris,R et al	wrong population
Evaluation of a nurse practitioner disease management model for chronic heart failure: a multi-site implementation study	2012	Congest Heart Fail	18	1	64-71	Lowery,J et al	wrong population
[CorBene: a new model for collaborative care of patients with congestive heart failure]	2012	Herz	37	1	56-58	Gysan,D.B et al	systematic review
[Home-based telemonitoring of simple vital signs to reduce hospitalization in heart failure patients: real-world data from a community-based hospital]	2011	G Ital Cardiol (Rome)	12	12	829-836	Palmieri,V et al	not found
Effectiveness of an educational self-management program for outpatients with chronic heart failure	2011	Jpn J Nurs Sci	8	2	140-152	Otsu,H et al	wrong population
Effectiveness of a self-care program in improving symptom distress and quality of life in congestive heart failure patients: a preliminary study	2011	J Nurs Res	19	4	257-266	Wang,S.P et al	wrong population
Home-based telemanagement in chronic heart failure: an 8-year single-site experience	2011	J Telemed Telecare	17	7	382-386	Giordano,A et al	wrong population

Clinical outcome of patients with chronic heart failure followed in a specialized heart failure center	2011	Isr Med Assoc J	13	8	468-473	Gotsman,I et al	wrong population
Automated home telephone self-monitoring reduces hospitalization in patients with advanced heart failure	2011	J Telemed Telecare	17	6	298-302	Kurtz,B et al	wrong population
Effectiveness and cost of a transitional care program for heart failure: a prospective study with concurrent controls	2011	Arch Intern Med	171	14	1238-1243	Stauffer,B.D et al	wrong population
Rationale and design of the Japanese heart failure outpatients disease management and cardiac evaluation (J-HOMECARE)	2011	J Cardiol	58	2	165-172	Tsuchihashi-Makaya,M et al	wrong publication type
Home monitoring cuts cardiac readmissions	2011	Hosp Case Manag	19	5	76-77	No authors listed	not found
Discharge to a skilled nursing facility and subsequent clinical outcomes among older patients hospitalized for heart failure	2011	Circ Heart Fail	4	3	293-300	Allen,L.A et al	wrong population
Swiss Interdisciplinary Management Programme for Heart Failure (SWIM-HF): a randomised controlled trial study of an outpatient inter-professional management programme for heart failure patients in Switzerland	2011	Swiss Med Wkly	141		w13171	Leventhal,M.E et al	wrong population
The impact of proactive chronic care management on hospital admissions in a German senior population	2011	Popul Health Manag	14		S29-S33	Hamar,B et al	wrong population
The effect of telehomecare on heart failure self care	2010	AMIA Annu Symp Proc	2010		71-75	Bowles,K.H et al	wrong population
Education and telephone monitoring by nurses of patients with heart failure: randomized clinical trial	2011	Arq Bras Cardiol	96	3	233-239	Domingues,F.B et al	wrong population
Health-related quality of life in a multicenter randomized controlled comparison of telephonic disease management and automated home monitoring in patients recently hospitalized with heart failure: SPAN-CHF II trial	2011	J Card Fail	17	2	151-157	Konstam,V et al	wrong population

Economic impact of remote patient monitoring: an integrated economic model derived from a meta-analysis of randomized controlled trials in heart failure	2011	Eur J Heart Fail	13	4	450-459	Klersy,C et al	systematic review
Telehealth in adult patients with congestive heart failure in long term home health care: a systematic review	2011	JBI Libr Syst Rev	9	30	1271-1296	Cherofsky,N et al	systematic review
Evaluation of the transitional care model in chronic heart failure	2010	Br J Nurs	19	22	1402-1407	Williams,G et al	wrong population
Cost-effectiveness of specialized multidisciplinary heart failure clinics in Ontario, Canada	2010	Value Health	13	8	915-921	Wijeysundera,H.C et al	wrong population
A randomized trial of telemonitoring heart failure patients	2010	J Healthc Manag	55	5	312-322	Tompkins,C et al	wrong population
The impact of a nurse-led care programme on events and physical and psychosocial parameters in patients with heart failure with preserved ejection fraction: a randomized clinical trial in primary care in Russia	2010	Eur J Gen Pract	16	4	205-214	Andryukhin,A et al	wrong population
Improved quality of life in Norwegian heart failure patients after follow-up in outpatient heart failure clinics: results from the Norwegian Heart Failure Registry	2010	Eur J Heart Fail	12	11	1247-1252	Hole,T et al	wrong population
Long-term implications of a single home-based educational intervention in patients with heart failure	2010	Heart Lung	39	6	S14-S22	Aguado,O et al	wrong population
Can a heart failure-specific cardiac rehabilitation program decrease hospitalizations and improve outcomes in high-risk patients?	2010	Eur J Cardiovasc Prev Rehabil	17	4	393-402	Davidson,P.M et al	wrong population
Nurse-led self-management group programme for patients with congestive heart failure: randomized controlled trial	2010	J Adv Nurs	66	7	1487-1499	Smeulders,E.S et al	wrong population
Case management for patients with chronic systolic heart failure in primary care: the HICMan exploratory randomised controlled trial	2010	Trials	11		56	Peters-Klimm,F et al	wrong population

Randomized trials of nursing interventions for secondary prevention in patients with coronary artery disease and heart failure: systematic review	2010	J Cardiovasc Nurs	25	3	207-220	Allen,J.K et al	systematic review
[Comparison between telephone and outpatient nursing management in patients with chronic heart failure in a large territorial area in Piedmont, Italy]	2010	G Ital Cardiol (Rome)	11	1	35-42	Mainardi,L et al	not found
A multicenter randomized controlled evaluation of automated home monitoring and telephonic disease management in patients recently hospitalized for congestive heart failure: the SPAN-CHF II trial	2010	J Card Fail	16	4	285-292	Weintraub,A et al	wrong population
Assessment of the clinical outcomes and cost-effectiveness of the management of systolic heart failure in Chinese patients using a home-based intervention	2010	J Int Med Res	38	1	242-252	Chen,Y.H et al	wrong population
Nurse-led interventions in heart failure care: patient and nurse perspectives	2010	Eur J Cardiovasc Nurs	9	4	226-232	Hoekstra,T et al	wrong population
Evidence-based nursing: the role of the advanced practice registered nurse in the management of heart failure patients in the outpatient setting	2010	Dimens Crit Care Nurs	29	2	57-62	Case,R et al	systematic review
Efficacy of multidisciplinary outpatient management (MOM) program in long term heart failure care	2010	South med J	103	2	131-137	Jain,R et al	wrong population
Primary care-based multifaceted, interdisciplinary medical educational intervention for patients with systolic heart failure: lessons learned from a cluster randomised controlled trial	2009	Trials	10		68	Peters-Klimm,F et al	wrong population
[Integrated care for patients with heart failure in Switzerland: a cost analysis]	2009	Praxis (Bern 1994)	98	15	809-815	Eichler,K et al	wrong population
Improving outcomes for older adults with heart failure: a randomized trial using a theory-guided nursing intervention	2010	J Nurs Care Qual	25	1	56-64	Duffy,J.R et al	wrong population
Outcomes of a home telehealth intervention for patients with heart failure	2009	J Telemed Telecare	15	1	46-50	Wakefield,B.J et al	wrong population

Community-based care for the specialized management of heart failure: an evidence-based analysis	2009	Ont Health Technol Assess Ser	9	17	1-42	Medical Advisory Secretariat	systematic review
Cost-effectiveness of nurse-led disease management for heart failure in an ethnically diverse urban community	2008	Ann Intern Med	149	8	540-548	Hebert,P.L et al	wrong population
[Value of basic and intensive management of patients with heart failure; results of a randomised controlled clinical trial]	2008	Ned Tijdschr Geneeskd	152	37	2016-2021	Jaarsma,T et al	not found
Tele-guidance of chronic heart failure patients enhances knowledge about the disease. A multi-centre, randomised controlled study	2008	Eur J Heart Fail	10	11	1136-1142	Balk,A.H et al	wrong population
Impact of telehealth on clinical outcomes in patients with heart failure	2008	Clin Nurs Res	17	3	182-199	Dansky,K.H et al	wrong population
Multidisciplinary management of elderly patients with chronic heart failure: five year outcome measures in death and survivor groups	2009	Eur J Cardiovasc Nurs	8	1	34-39	Austin,J et al	wrong population
Cost-effectiveness of a disease management programme for secondary prevention of coronary heart disease and heart failure in primary care	2008	Heart	94	12	1601-1606	Turner,D.A et al	wrong population
Survival and hospitalization in a nurse-led domiciliary intervention for elderly heart failure patients	2008	J Cardiovasc Med (Hagerstown)	9	5	470-475	Rondinini,L et al	wrong population
Five-year follow-up findings from a randomized controlled trial of cardiac rehabilitation for heart failure	2008	Eur J Cardiovasc Prev Rehabil	15	2	162-167	Austin,J et al	wrong population
Cost-effective care a phone call away: a nurse-managed telephonic program for patients with chronic heart failure	2008	Nurs Econ	26	1	41-44	Slater,M.R et al	not found
Telemonitoring of heart failure patients and their caregivers: a pilot randomized controlled trial	2008	Prog Cardiovasc Nurs	23	1	18-26	Schwarz,K.A et al	wrong population

Lessons learned from a multidisciplinary heart failure clinic for older women: a randomised controlled trial	2008	Age Ageing	37	3	282-287	Azad,N et al	wrong population
Effect of moderate or intensive disease management program on outcome in patients with heart failure: Coordinating Study Evaluating Outcomes of Advising and Counseling in Heart Failure (COACH)	2008	Arch Intern Med	168	3	316-324	Jaarsma,T et al	wrong population
Multicenter randomised trial on home-based telemanagement to prevent hospital readmission of patients with chronic heart failure	2009	Int J Cardiol	131	2	192-199	Giordano,A et al	wrong population
Use of telehealth by older adults to manage heart failure	2008	Res Gerontol Nurs	1	1	25-32	Dansky,K.H et al	not found
A randomized controlled trial of a community nurse-supported hospital discharge programme in older patients with chronic heart failure	2008	J Clin Nurs	17	1	109-117	Kwok,T et al	wrong population
Impact of the implementation of telemanagement on a disease management program in an elderly heart failure cohort	2007	Prog Cardiovasc Nurs	22	4	196-200	Gambetta,M et al	wrong population
A systematic review of nurse-assisted case management to improve hospital discharge transition outcomes for the elderly	2007	Prof Case Manag	12	6	330-336	Chiu,W.K et al	systematic review
The use of supportive-educative and mutual goal-setting strategies to improve self-management for patients with heart failure	2007	Home Healthc Nurse	25	8	502-510	Kline,K.S et al	wrong population
Impact of a specialized outpatient heart failure follow-up program on hospitalization frequency and functional status of patients with advanced heart failure	2007	Rev Port Cardiol	26	4	335-343	Correia,J et al	wrong intervention
[Heart failure: the importance of a disease management program]	2007	G Ital Cardiol (Rome)	8	6	353-358	Fabbri,G et al	not found
A systematic review of the benefits of home telecare for frail elderly people and those with long-term conditions	2007	J Telemed Telecare	13	4	172-179	Barlow,J et al	systematic review

Efficacy of community-based multidisciplinary disease management of chronic heart failure	2007	Singapore Med J	48	6	528-531	Omar,A.R et al	wrong population
Lack of long-term benefits of a 6-month heart failure disease management program	2007	J Card Fail	13	4	287-293	Nguyen,V et al	wrong population
Improved cost-effectiveness for management of chronic heart failure by combined home-based intervention with clinical nursing specialists	2007	J Formos Med Assoc	106	4	313-319	Ho,Y.L et al	wrong population
Two-year outcome of a prospective, controlled study of a disease management programme for elderly patients with heart failure	2007	J Cardiovasc Med (Hagerstown)	8	5	324-329	Del,Sindaco D et al	wrong population
[New multidisciplinary heart failure care program (six-month preliminary observation)]	2006	Pol Merkur Lekarski	21	126	511-515	Wierzchowiecki, M et al	not found
Home-based palliative care study: site of death, and costs of medical care for patients with congestive heart failure, chronic obstructive pulmonary disease, and cancer	2005	J Soc Work End Life Palliat Care	1	3	37-56	Enguidanos,S.M et al	wrong intervention
The effect of frontloading visits on patient outcomes	2007	Home Healthc Nurse	25	2	103-109	Rogers,J et al	wrong population
Motivational interviewing to change quality of life for people with chronic heart failure: a randomised controlled trial	2008	Int J Nurs Stud	45	4	489-500	Brodie,D.A et al	wrong population
Applying research evidence to optimize telehomecare	2007	J Cardiovasc Nurs	22	1	5-15	Bowles,K.H et al	systematic review
Extending the horizon in chronic heart failure: effects of multidisciplinary, home-based intervention relative to usual care	2006	Circulation	114	23	2466-2473	Inglis,S.C. et al	wrong population
Advanced practice nurse strategies to improve outcomes and reduce cost in elders with heart failure	2006	Dis Manag	9	5	302-310	McCauley,K.M et al	systematic review
Telephone follow-up of self-care behaviour after a single session education of patients with heart failure in primary health care	2007	Eur J Cardiovasc Nurs	6	2	153-159	Holst,M et al	wrong population
Effects of nurse management on the quality of heart failure care in minority communities: a randomized trial	2006	Ann Intern Med	145	4	273-283	Sisk,J.E et al	wrong population

Telephone interventions by nursing students: improving outcomes for heart failure patients in the community	2006	J Community Health Nurs	23	3	137-146	Wheeler,E.C et al	wrong population
Exercise self-efficacy in older women with diastolic heart failure: results of a walking program and education intervention	2006	J Gerontol Nurs	32	7	31-39	Gary,R.	not found
Lack of improvement of clinical outcomes by a low-cost, hospital-based heart failure management programme	2006	J Cardiovasc Med (Hagerstown)	7	8	614-622	Nucifora,G et al	wrong population
Improving care at lower cost for end-stage heart and lung disease: integrating end of life planning with home care	2006	Mo Med	103	2	146-151	Edes,T.E et al	not found
A motivational counseling approach to improving heart failure self-care: mechanisms of effectiveness	2006	J Cardiovasc Nurs	21	3	232-241	Riegel,B et al	wrong population
Randomized controlled trial of telephone case management in Hispanics of Mexican origin with heart failure	2006	J Card Fail	12	3	211-219	Riegel,B et al	wrong population
Home telehealth improves clinical outcomes at lower cost for home healthcare	2006	Telemed J E Health	12	2	128-136	Finkelstein,S.M et al	wrong population
The influences of postdischarge management by nurse practitioners on hospital readmission for heart failure	2006	J Am Acad Nurse Pract	18	4	154-160	Delgado-Passler,P et al	systematic review
Prolonged effects of a home-based intervention in patients with chronic illness	2006	Arch Intern Med	166	6	645-650	Pearson,S et al	wrong population
The impact of nurse-directed patient education on quality of life and functional capacity in people with heart failure	2006	J Am Acad Nurse Pract	18	3	116-123	Kutzleb,J et al	wrong population
Computer-based education for patients with chronic heart failure. A randomised, controlled, multicentre trial of the effects on knowledge, compliance and quality of life	2006	Patient Educ Couns	64	1	128-135	Stromberg,A et al	wrong population

[Outpatient medical and nurse management program in patients with chronic heart failure in a large territorial area in Piedmont. Four years of follow-up]	2005	Ital Heart J Suppl	6	12	812-820	Conte,M.R et al	not found
Benefits of comprehensive inpatient education and discharge planning combined with outpatient support in elderly patients with congestive heart failure	2005	Congest Heart Fail	11	6	315-321	Anderson,C et al	wrong population
Disease management produces limited quality-of-life improvements in patients with congestive heart failure: evidence from a randomized trial in community-dwelling patients	2005	Am J Manag Care	11	11	701-713	Smith,B et al	wrong population
Multidisciplinary and multisetting team management programme in heart failure patients affects hospitalisation and costing	2006	Int J Cardiol	111	3	377-385	Piepoli,M.F et al	wrong population
[Randomised clinical trial to evaluate the efficacy of a multi-factorial intervention to reduce hospitalisation and improve the quality of life of patients with heart failure]	2005	Aten Primaria	36	5	280-283	Brotons,C et al	wrong publication type
Effects of a nurse-based heart failure clinic on drug utilization and admissions in a community hospital setting	2005	Scand Cardiovasc J	39	4	199-205	Andersen,M.K et al	wrong population
Heart failure disease management: implementation and outcomes	2005	Whellan DJ	13	5	231-239	Whellan,D.J	systematic review
Effect of home-based telecardiology on chronic heart failure: costs and outcomes	2005	J Telemed Telecare	11		16-18	Scalvini,S et al	wrong population
Impact of care at a multidisciplinary congestive heart failure clinic: a randomized trial	2005	CMAJ	173	1	40-45	Ducharme,A et al	wrong population
Metaanalysis and review of heart failure disease management randomized controlled clinical trials	2005	Am Heart J	149	4	722-729	Whellan,D.J et al	systematic review
Just-in-time evidence-based e-mail "reminders" in home health care: impact on patient outcomes	2005	Health Serv Res	40	3	865-885	Feldman,P.H et al	wrong population

Just-in-time evidence-based e-mail "reminders" in home health care: impact on nurse practices	2005	Health Serv Res	40	3	849-864	Murtaugh,C.M et al	wrong population
Systematic review of multidisciplinary interventions in heart failure	2005	Heart	91	7	899-906	Holl and ,R et al	systematic review
Randomized trial of a nurse-administered, telephone-based disease management program for patients with heart failure	2005	J Card Fail	11	5	358-365	Dunagan,W.C et al	wrong population
State of the science: posthospitalization nursing interventions in congestive heart failure	2005	ANS Adv Nurs	28	2	175-190	Hamner,J.B	systematic review
Patient's education by nurse: what we really do achieve?	2005	Eur J Cardiovasc Nurs	4	2	107-111	Gonzalez,B et al	not found
Noninvasive home telemonitoring for patients with heart failure at high risk of recurrent admission and death: the Trans-European Network-Home-Care Management System (TEN-HMS) study	2005	J Am Coll Cardiol	45	10	1654-1664	Clel and ,J.G et al	wrong population
Prospective evaluation of an outpatient heart failure disease management program designed for primary care: the Oregon model	2005	J Card Fail	11	4	293-298	Hershberger,R.E et al	wrong population
Early outcomes of a care coordination-enhanced telehome care program for elderly veterans with chronic heart failure	2005	Telemed J E Health	11	1	20-27	Schofield,R.S et al	wrong population
Randomised controlled trial of cardiac rehabilitation in elderly patients with heart failure	2005	Eur J Heart Fail	7	3	411-417	Austin,J et al	wrong population
Patients with heart failure in primary health care: effects of a nurse-led intervention on health-related quality of life and depression	2005	Eur J Heart Fail	7	3	393-403	Martensson,J et al	wrong population
Effects of a nurse-led, clinic and home-based intervention on recurrent hospital use in chronic heart failure	2005	Eur J Heart Fail	7	3	377-384	Thompson,D.R et al	wrong population
A multicenter disease management program for hospitalized patients with heart failure	2004	J Card Fail	10	6	473-480	Tsuyuki,R.T et al	wrong population

The effects of nursing interventions to enhance mental health and quality of life among individuals with heart failure	2004	Appl Nurs Res	17	4	248-256	Scott,L.D et al	wrong population
Implementation of guidelines for management of heart failure in heart failure clinic: effects beyond pharmacological treatment	2004	Int J Cardiol	97	3	411-416	Lainscak,M	wrong population
Long-term healthcare and cost outcomes of disease management in a large, randomized, community-based population with heart failure	2004	Circulation	110	23	3518-3526	Galbreath,A.D et al	wrong population
Care management for low-risk patients with heart failure: a randomized, controlled trial	2004	Ann Intern Med	141	8	606-613	DeBusk,R.F et al	wrong population
Managing congestive heart failure using home telehealth	2004	Home Healthc Nurse	22	10	719-722	Schneider,N.M	wrong population
Heart failure clinics and outpatient management: review of the evidence and call for quality assurance	2004	Eur Heart J	25	18	1596-1604	Gustafsson,F et al	systematic review
Multidisciplinary strategies for the management of heart failure patients at high risk for admission: a systematic review of randomized trials	2004	J Am Coll Cardiol	44	4	810-819	McAlister,F.A et al	systematic review
Limited long term effects of a management programme for heart failure	2004	Heart	90	9	1010-1015	Mejhert,M et al	wrong population
A literature review of cardiovascular disease management programs in managed care populations	2004	J Manag Care Pharm	10	4	326-344	Ara,S	systematic review
A randomized intervention to improve heart failure outcomes in community-based home health care	2004	Home Health Care Serv Q	23	1	1-23	Feldman,P.H et al	wrong population
[Case management for patients with congestive heart failure under ambulatory care--a critical review]	2004	Z Arztl Fortbild Qualitatssich	98	2	143-154	Gensichen,J et al	not found
Transitional care of older adults hospitalized with heart failure: a randomized, controlled trial	2004	J Am Geriatr Soc	52	5	675-684	Naylor,M.D et al	wrong population
The comprehensive care team: a controlled trial of outpatient palliative medicine consultation	2004	Arch Intern Med	164	1	83-91	Rabow,M.W et al	wrong population
Effects of education, self-care instruction and physical exercise on patients with chronic heart failure	2003	Z Kardiol	92	12	985-993	Miche,E et al	wrong population

A disease management program for heart failure: collaboration between a home care agency and a care management organization	2003	Lippincotts Case Manag	8	6	265-273	Gorski,L.A et al	wrong population
Palliative care management: a Veterans Administration demonstration project	2003	J Palliat Med	6	5	831-839	Rosenfeld,K et al	background article
A systematic review of telemonitoring for the management of heart failure	2003	Eur J Heart Fail	5	5	583-590	Louis,A.A et al	systematic review
Use of the short form 36 in a primary care based disease management program for patients with congestive heart failure	2003	Dis Manag	6	2	111-117	Sidorov,J et al	wrong population
[Management programs for elderly patients with chronic heart failure]	2003	Clin Ter	154	3	199-206	Pulignano,G et al	not found
Cardiac rehabilitation with nurse care management and telephonic interactions at a community hospital: program evaluation of participation and lipid outcomes	2003	Lippincotts Case Manag	8	4	141-157	Harris,D.E et al	wrong population
Effects of an exercise adherence intervention on outcomes in patients with heart failure	2003	Rehabil Nurs	28	4	117-122	Duncan,K et al	wrong population
Uptake of self-management strategies in a heart failure management programme	2003	Eur J Heart Fail	5	3	371-380	Wright,S.P et al	wrong population
A randomized trial of telenursing to reduce hospitalization for heart failure: patient-centered outcomes and nursing indicators	2003	Home Health Care Serv Q	22	1	1-20	Jerant,A.F et al	wrong population
Case management in a heterogeneous congestive heart failure population: a randomized controlled trial	2003	Arch Intern Med	163	7	809-817	Laramee,A.S et al	wrong population
Heart failure disease management: impact on hospital care, length of stay, and reimbursement	2003	Congest Heart Fail	9	2	77-83	Discher,C.L et al	wrong population
Managing heart failure in the community; role of the nurse specialist	2001	Health Bull (Edinb)	59	5	340-342	Smith,M et al	not found
Outcomes of chronic heart failure	2003	Arch Intern Med	163	3	347-352	Benatar,D et al	wrong population

Telemanagement of heart failure: a diuretic treatment algorithm for advanced practice nurses	2002	Heart Lung	31	5	340-347	Mueller,T.M et al	background article
Symptom status and quality-of-life outcomes of home-based disease management program for heart failure patients	2002	Outcomes Manag	6	4	161-168	Todero,C.M et al	wrong population
Cost/utility ratio in chronic heart failure: comparison between heart failure management program delivered by day-hospital and usual care	2002	J Am Coll Cardiol	40	7	1259-1266	Capomolla,S et al	wrong population
Heart failure management: multidisciplinary care has intrinsic benefit above the optimization of medical care	2002	J Card Fail	8	3	142-148	McDonald,K et al	wrong population
Home-based intervention in congestive heart failure: long-term implications on readmission and survival	2002	Circulation	105	24	2861-2866	Stewart,S et al	wrong population
[Impact of a nurse-based heart failure management program on hospitalization rate, functional status, quality of life, and medical costs]	2002	Ital Heart J Suppl	3	5	532-538	Chinaglia,A et al	not found
Effect of a heart failure clinic on survival and hospital readmission in patients discharged from acute hospital care	2002	Eur J Heart Fail	4	3	353-359	Azevedo,A et al	wrong population
Detecting early clinical deterioration in chronic heart failure patients post-acute hospitalisation-a critical component of multidisciplinary, home-based intervention?	2002	Eur J Heart Fail	4	3	345-351	Stewart,S et al	wrong population
Quantification of interventions and outcomes in an outpatient telemanagement and care management congestive heart failure program	2000	Congest Heart Fail	6	3	146-151	Palladino,M et al	wrong population
Quality of life of individuals with heart failure: a randomized trial of the effectiveness of two models of hospital-to-home transition	2002	Med Care	40	4	271-282	Harrison,M. et al	wrong population
APN spells success for a heart failure program	2002	Nurs Manage	33	2	46-48	Dahl,J et al	background article
Improving the quality of home care for patients with heart failure	2002	Caring	21	3	10-14	Gorski,L.A	not found

Effect of a standardized nurse case-management telephone intervention on resource use in patients with chronic heart failure	2002	Arch Intern Med	162	6	705-712	Riegel,B et al	wrong population
Use of a clinical care map for the management of congestive heart failure in a community hospital	2001	Congest Heart Fail	7	1	37-42	Lanzieri,M et al	wrong population
A randomized trial of the efficacy of multidisciplinary care in heart failure outpatients at high risk of hospital readmission	2002	J Am Coll Cardiol	39	3	471-480	Kasper,E.K et al	wrong population
Randomized, controlled trial of integrated heart failure management: The Auckland Heart Failure Management Study	2002	Eur Heart J	23	2	139-146	Doughty,R.N et al	wrong intervention
Compliance and effectiveness of 1 year's home telemonitoring. The report of a pilot study of patients with chronic heart failure	2001	Eur J Heart Fail	3	6	723-730	de,Lusignan S et al	wrong population
Reducing the cost of frequent hospital admissions for congestive heart failure: a randomized trial of a home telecare intervention	2001	Med Care	39	11	1234-1245	Jerant,A et al	wrong population
Cost-effective outpatient management of persons with heart failure	2001	Prog Cardiovasc Nurs	16	2	50-56	Henrick,A	wrong population
A systematic review of randomized trials of disease management programs in heart failure	2001	Am J Med	110	5	378-384	McAlister,F.A et al	systematic review
Effectiveness of team-managed home-based primary care: a randomized multicenter trial	2000	JAMA	284	22	2877-2885	Hughes,S.L et al	wrong population
Which patients with heart failure respond best to multidisciplinary disease management?	2000	J Card Fail	6	4	290-299	Riegel,B et al	wrong population
A pilot study of radiotelemetry for continuous cardiopulmonary monitoring of patients at home	2000	J Telemed Telecare	6		S119-S122	de,Lusignan S et al	wrong population
A controlled pilot study in the use of telemedicine in the community on the management of heart failure--a report of the first three months	1999	Stud Health Technol Inform	64		126-137	de,Lusignan S et al	not found
Impact of a nurse-managed heart failure clinic: a pilot study	2000	Am J Crit Care	9	2	140-146	Paul,S	not found

Enhanced access to primary care for patients with congestive heart failure. Veterans Affairs Cooperative Study Group on Primary Care and Hospital Readmission	1999	Eff Clin Pract	2	5	201-209	Oddone,E.Z et al	wrong population
Implementing a congestive heart failure disease management program to decrease length of stay and cost	1999	J Cardiovasc Nurs	14	1	55-74	Knox,D et al	not found
Effect of a home monitoring system on hospitalization and resource use for patients with heart failure	1999	Am Heart J	138	4	633-640	Heidenreich,P.A et al	wrong population
A community hospital-based congestive heart failure program: impact on length of stay, admission and readmission rates, and cost	1999	Am J Manag Care	5	1	37-43	Rauh,R.A et al	wrong population
Heart failure disease management: a critical review	1999	J Card Fail	5	1	64-75	Rich,M.W	systematic review
Comprehensive multidisciplinary programs for the management of patients with congestive heart failure	1999	J Gen Intern Med	14	2	130-135	Philbin,E.F	systematic review
Cost effective management programme for heart failure reduces hospitalisation	1998	Heart	80	5	442-446	Cline,C.M et al	wrong population
Effects of a home-based intervention among patients with congestive heart failure discharged from acute hospital care	1998	Arch Intern Med	158	10	1067-1072	Stewart,S et al	wrong population
Using case management with clinical plans to improve patient outcomes	1998	Home Healthc Nurse	16	1	15-20	Huggins,C.M et al	background article
Symptomatic improvement and reduced hospitalization for patients attending a cardiomyopathy clinic	1997	Clin Cardiol	20	11	949-954	Smith,L.E et al	wrong population
Assessment--patients, chronic heart failure, and home care	1997	Caring	16	6	20-2, 24	Lazarre,M et al	not found
A study of the relationship between home care services and hospital readmission of patients with congestive heart failure	1997	Home Healthc Nurse	15	2	123-129	Martens,K.H et al	wrong population

A comprehensive management system for heart failure improves clinical outcomes and reduces medical resource utilization	1997	Am J Cardiol	79	1	58-63	West,J.A et al	wrong population
Disease management for chronic congestive heart failure	1996	J Cardiovasc Nurs	11	1	54-62	Brass-Mynderse,N.J	background article
Does increased access to primary care reduce hospital readmissions? Veterans Affairs Cooperative Study Group on Primary Care and Hospital Readmission	1996	N Engl J Med	334	22	1441-1447	Weinberger,M et al	wrong population
The effect of a nurse-managed CHF clinic on patient readmission and length of stay	1996	Home Healthc Nurse	14	5	351-356	Lasater,M.	background article
The connection delivery model: care across the continuum	1996	Nurs Manage	27	5	34, 36	Donlevy,J.A et al	not found
A multidisciplinary intervention to prevent the readmission of elderly patients with congestive heart failure	1995	N Engl J Med	333	18	1190-1195	Rich,M.W et al	wrong population
Home monitoring for congestive heart failure patients	1995	Caring	14	8	53-54	Miller,P.Z	wrong population
Prevention of readmission in elderly patients with congestive heart failure: results of a prospective, randomized pilot study	1993	J Gen Intern Med	8	11	585-590	Rich,M.W et al	wrong population
Improving Heart Failure Self-Management Support by Actively Engaging Out-of-Home Caregivers: Results of a Feasibility Study	2013	Congest Heart Fail	14	1		Piette,J.D et al	wrong population
Blended collaborative care to treat heart failure and comorbid depression: Rationale and Study Design of the Hopeful Heart Trial	2019	Psychosom Med	81	6	495-505	Herbeck,Belnap B et al	wrong population
Application of transitional care model in patients with chronic heart disease: A case-controlled intervention study	2018	Rev Latam HTA	13	3	285-290	Rezapour-Nasrabad,R	wrong population
Clinical investigation on the nursing needs of heart failure patients and analysis of planning nursing intervention effect	2017	Biomedical Research	28	22	10084-10087	Chen,C et al	wrong population

Palliative Care Interventions for Patients with Heart Failure: A Systematic Review and Meta-Analysis	2017	J Palliat Med	20	1	84-92	Diop,M.S et al	systematic review
Case conference primary-secondary care planning at end of life can reduce the cost of hospitalisations	2016	BMC Palliat Care	15	1		Hollingworth,S et al	wrong population
Primary results of the Patient-Centered Disease Management (PCDM) for heart failure study a randomized clinical trial	2015	JAMA Intern Med	175	5	725-732	Bekelman,D.B et al	wrong population
A Mobile Health Intervention Supporting Heart Failure Patients and Their Informal Caregivers: A Randomized Comparative Effectiveness Trial	2015	J Med Internet Res	17	6	e142	Piette,J.D et al	wrong population
Program evaluation of remote heart failure monitoring: healthcare utilization analysis in a rural regional medical center	2015	Telemed J E Health	21	3	157-162	Riley,W.T et al	wrong population
Cardiauvergne: Heart failure home management and remote monitoring system. [French]	2014	Soins	3	4	169-176	Eschalier,R et al	wrong population
Manpower and outpatient clinic workload for remote monitoring of patients with cardiac implantable electronic devices: Data from the HomeGuide registry	2014	J Cardiovasc Electrophysiol	25	11	1216-1223	Ricci,R.P et al	wrong population
Home-based advance care programme is effective in reducing hospitalisations of advanced heart failure patients: A clinical and healthcare cost study	2013	Ann Acad Med Singap	42	9	466-471	Wong,R.C.C et al	not found
Remote monitoring after recent hospital discharge in patients with heart failure: A systematic review and network meta-analysis	2013	Heart	99	23	1717-1726	Pandor, A et al	systematic review
Mode of action and effects of standardized collaborative disease management on mortality and morbidity in patients with systolic heart failure the interdisciplinary network for heart failure (INH) study	2012	Circ Heart Fail	5	1	25-35	Angermann,C.E et al	wrong population

Outcomes of a telehealth intervention for homebound older adults with heart or chronic respiratory failure: a randomized controlled trial	2012	Gerontologist	52	4	541-552	Gellis,Z.D et al	wrong population
Hospital initiative reduces heart failure readmissions	2012	Hosp Case Manag	20	11	161-163	No authors listed	not found
The "Kremser model": Successful disease management programme for patients with chronic heart failure. [German]	2011	Journal fur Kardiologie	18	9	299-306	Bohmer,A et al	wrong population
Telemonitoring with case management for seniors with heart failure	2011	Am J Manag Care	17	3	e71-e79	Wade,M.J et al	wrong population
Clinical trials update from the European Society of Cardiology Heart Failure meeting 2011: TEHAF, WHICH, CARVIVA, and atrial fibrillation in GISSI-HF and EMPHASIS-HF	2011	Eur J Heart Fail	13	10	1147-1151	Clel and ,J.G.F et al	wrong population
Improving heart failure in home care with chronic disease management and telemonitoring	2010	Home Healthc Nurse	28	10	606-617	Hall,P et al	background article
The effect of shared medical visits on knowledge and self-care in patients with heart failure: A pilot study	2009	Heart Lung	38	1	25-33	Yehle,K.S et al	wrong population
Telehealth helps hospital cut readmissions by 75%	2007	Healthcare Benchmarks Qual Improv	14	8	92-94	No authors listed	not found
Therapeutic education and multidisciplinary approaches in heart failure. [French]	2009	Medecine Therapeutique - Cardio	4	1	79-87	Assyag,P et al	not found
Community cardiology clinics for secondary prevention of coronary heart disease and heart failure in primary care	2008	Cardiol Review	25	12	64-67	Khunti,K et al	not found
Impact of specialist care in patients with newly diagnosed heart failure: A randomised controlled study	2007	Int J Cardiol	115	2	196-202	Rao,A et al	wrong population
Feasibility and efficacy of a hybrid post-discharge service for patients with acute heart failure - The tyrolean model. [German]	2007	Journal fur Kardiologie	14	1	13-17	Metzler,B et al	not found

Alternative healthcare models for patients with heart failure: A systematic review. [Spanish]	2006	Revista de Calidad Asistencial	21	1	51-60	Morales,J.M et al	systematic review
Tele-homecare for chronically-ill patients: Improved outcomes and new developments	2004	Journal on Information Technology in Healthcare	2	4	251-262	Robinson,S et al	wrong population
Management of the Patient with Congestive Heart Failure in the Home Care and Palliative Care Setting	2004	Annals of Long-Term Care	12	1	33-37	Quaglietti,S et al	not found
A community-based service for patients with congestive cardiac failure: Impact on quality of life scores	2004	British Journal of Cardiology	11	1	75-79	Williams,H et al	not found
Interdisciplinary team-based management of heart failure	2003	Disease Management and Health Outcomes	11	2	87-94	Di Salvo,T.G et al	background article
Care management interventions for older patients with congestive heart failure	2003	American Journal of Managed Care	9	6	447-459	Windham,B.G et al	not found
Establishment of a nurse-led heart failure clinic. Design and baseline data from the first two years. [Danish]	2003	Ugeskrift for Laeger	165	7	686-690	Galatius,S et al	not found
Specialist Nurse-Led Intervention in Outpatients with Congestive Heart Failure: Impact on Clinical and Economic Outcomes	2003	Disease Management and Health Outcomes	11	11	693-698	Palmer,N.D et al	background article
Heart failure programs and comprehensive management in heart failure. [Italian]	2002	Monaldi Archives for Chest Disease	58	2	135-139	Di,Lenarda A et al	background article
Standardized telephonic case management in a Hispanic heart failure population: An effective intervention	2002	Disease Management and Health Outcomes	10	4	241-249	Riegel,B et al	wrong population
An economic analysis of specialist heart failure nurse management in the U.K.: Can we afford not to implement it?	2002	European Heart Journal	23	17	1369-1378	Stewart,S et al	wrong population
Optimising delivery of care for chronic heart failure	2000	Journal of Clinical Excellence	1	4	209-215	Clark,A.L et al	not found

Cost-effectiveness analysis in clinical practice: The case of heart failure	1999	Archives of Internal Medicine	159	15	1690-1700	Rich,M.W et al	systematic review
Structured telephone support or nonÂƒ__invasive telemonitoring for patients with heart failure	2015	Cochrane Database of Syst Rev		10	CD007228	Inglis,S.C et al	systematic review
A new programme of multidisciplinary care for patients with heart failure in PoznaÂ ": one-year follow-up	2006	Kardiol Pol	64	10	1063-70	Wierzchowiecki, M et al	not found
Efficacy of a Physician-Led Multiparametric Telemonitoring System in Very Old Adults with Heart Failure	2015	J Am Geriatr Soc	63	6	1175-80	Pedone,C et al	wrong population
A randomised controlled trial of a facilitated home-based rehabilitation intervention in patients with heart failure with preserved ejection fraction and their caregivers: the REACH-HFpEF Pilot Study	2018	BMJ Open	8	4	e019649	Lang,C.C et al	wrong population
Evaluation of a home-based intervention in heart failure patients. Results of a randomized study	2005	Rev Esp Cardiol	58	6	618-25	Morcillo,C et al	wrong population
Economic evaluation of Manitoba Health Lines in the management of congestive heart failure	2013	Healthc Policy	9	2	36-50	Cui,Y et al	wrong population
Physical function and quality of life in older women with diastolic heart failure: effects of a progressive walking program on sleep patterns	2007	Prog Cardiovasc Nurs	22	2	72-80	Gary,R et al	wrong population
Randomized, controlled evaluation of short- and long-term benefits of heart failure disease management within a diverse provider network: the SPAN-CHF trial	2004	Circulation	110	11	1450-5	Kimmelstiel,C et al	wrong population
Cognitive Behavior Therapy for Depression and Self-Care in Heart Failure Patients: a Randomized Clinical Trial	2015	JAMA Intern Med	175	11	1773-82	Freedl and ,K.E et al	wrong population
Outcomes of home management methods for chronic heart failure	2002	Doctoral thesis				Bondmass,M.D	not found

Effects of three different disease management programs on outcomes in patients hospitalized with heart failure: a randomized trial	2012	Med Clin (Barc)	138	5	192-8	Gamez-Lopez,A.L et al	wrong population
A randomized controlled trial of self-management programme improves health-related outcomes of older people with heart failure	2013	J Adv Nurs	69	11	2458-69	Jung-Hua, S et al	wrong population
A Review: Discharge Navigation and Its Effect on Heart Failure Readmissions	2014	Prof Case Manag	19	5	224-234	Schell,W	systematic review
Advanced Practice Nurse Intervention and Heart Failure Readmissions	2018	Doctoral thesis				Reynolds,T	wrong population
Case management for patients with heart failure: a quality improvement intervention	2005	J Gerontol Nurs	31	5	20-28	Miller,L.C et al	not found
Chronic Heart Failure Management in Rural Primary Care	2016	J Dr Nurs Pract	9	1	20-28	Kreifels,E et al	not found
Clinical pathway versus a usual plan of care for patients with congestive heart failure: what's the difference?...part 1 of a two-part series	2001	Home Healthc Nurse	19	3	142-150	Hoskins,L.M et al	wrong population
Communication Between the Primary Care Physician and the Hospitalist at theTime of Patient Admission	2012	JCOM	19	10	453-459	Hennrikus,E	wrong population
Comparison of Health Buddy with traditional approaches to heart failure management	2003	Fam Community Health	26	4	275-288	LaFramboise,L.M et al	wrong population
Effectiveness of Interprofessional Care Teams on Reducing Hospital Readmissions in Patients with Heart Failure: A Systematic Review	2018	MedSurg Nursing	27	3	177-185	Shah,B	systematic review
Effects of education on self-care behaviour and quality of life in patients with chronic heart failure	2010	The World of Critial Care Nursing	7	2	115-121	Enç, N et al	wrong population
Effects of home-based care program on symptom alleviation and well-being among persons with chronic heart failure	2008	Thai Journal of Nursing Research	12	1	25-39	Wongpiriyayothar ,A et al	not found
Implementing a congestive heart failure outpatient program	1999	not listed	6	7	14-18	Schwabauer,N.J et al	not found

Incorporating Technology to Decrease Heart Failure Readmission Rates	2018	Doctoral thesis				Thames,V	wrong population
Nursing approach to a patient with cardiac insufficiency in Primary Care	2012	Metas de enfemería	15	10	56-61	Prats-Guardiola, M et al	not found
Randomized control trial of a self-management intervention for heart failure older adults in Northern Taiwan	2019	Australian Collage of Nursing	26	2	288-294	Shao,J et al	wrong population
Research corner. Utilization of home health care services by elderly patients with heart failure	1998	not listed	10	4	66-73	Moulton,P.J et al	wrong population
Research on reducing hospitalizations in patients with chronic heart failure	2010	Home Healthc Nurse	28	6	335-340	McGhee,G et al	background article
Self-care and improved outcomes: an intervention by heart failure nurse specialists	2016	British J Cardiac Nurs	11	2	82-88	MacInnes,J et al	wrong population
Technology-enhanced practice for patients with chronic cardiac disease: Home implementation and evaluation	2010	Heart Lung	39	6	S34-S46	Brennan,P.F et al	wrong population
Telephone-based, nursing follow-up of patients with heart failure	2011	not listed	14	3	22-26	Just,M et al	wrong population
The Influence of Remote Monitoring on Clinical Decision Making	2016	Home Healthc Manag Prac	28	2	86-93	Williams,C et al	not found
The role of community-based nursing interventions in improving outcomes for individuals with cardiovascular disease: A systematic review	2019	Int J Nurs Stud	100		N-N	Han,E et al	systematic review
The impact of a community-based heart failure multidisciplinary team clinic on healthcare utilization and costs	2022	ESC Heart Fail.	9	1	676–684	Weinstein et al	wrong intervention
Examining Adherence and Dose Effect of an Early Palliative Care Intervention for Advanced Heart Failure Patients	2021	J Pain Symptom Manage.	62	3	471-481	Wells, R	wrong study design
Association between communitybased nurse practitioner support, self-care behaviour and quality of life in patients with chronic heart failure	2021	Australian Journal of Advanced Nursing	38	3	25-32	Sheau Huey, Chen	wrong population

An inpatient multidisciplinary educational approach to reduce 30-day heart failure readmissions	2021	Saudi Pharm J	29	4	337-342	Aljabri, A	wrong population
A Randomized Controlled Trial of Heart Failure Disease Management in Skilled Nursing Facilities	2022	J Am Med Dir Assoc	23	3	359-366	Boxer, R. S. et al	wrong population
Challenges of Telemonitoring Programs for Complex Chronic Conditions: Randomized Controlled Trial With an Embedded Qualitative Study	2022	J Med Internet Res	24	1	e31754	Ware, P et al	wrong population
Disease Management in Skilled Nursing Facilities Improves Outcomes for Patients With a Primary Diagnosis of Heart Failure	2021	Journal of the American Medical Directors Association	0	0	367-372	Weerahandi, H et al	wrong population
Disease management with home telemonitoring aimed at substitution of usual care in the Netherlands: Post-hoc analyses of the e-Vita HF study	2022	J Cardiol	79	1	1-5	Brons, M et al	wrong population
Efficacy of Blended Collaborative Care for Patients With Heart Failure and Comorbid Depression: A Randomized Clinical Trial	2021	JAMA Intern Med	181	10	1369-1380	Rollman, B. L et al	wrong population
Implementation of early follow-up care after heart failure hospitalization	2021	Am J Manag Care	27	2	E42-e47	Dev, S et al	wrong population
Managing patients with heart failure: contemporary real-world experience	2022	BMC research notes	15	1	41	Siddiqui, M et al	wrong population
The effectiveness of a nurse-led home-based heart failure self-management programme (the HOM-HEMP) for patients with chronic heart failure: A three-arm stratified randomized controlled trial	2021	Int J Nurs Stud	122	0	104026	Jiang, Y et al	wrong population
The Effect of Rehospitalization and Emergency Department Visits on Subsequent Adherence to Weight Telemonitoring	2021	J Cardiovasc Nurs	36	5	482-488	Haynes, S. C et al	wrong population
The Impact of Nurse-Led Cardiac Rehabilitation on Quality of Life and Biophysiological Parameters in Patients With Heart Failure: A Randomized Clinical Trial	2021	Journal of Nursing Research	29	1	e130-e130	Arjunan et al	wrong population

A quasi-experimental study examining a nurse-led educational program to improve disease knowledge and self-care for patients with acute decompensated heart failure with reduced ejection fraction	2021	Adv Clin Exp Med	0	0	-	Kolasa, J et al	wrong population
Effect of nurse-led hospital-to-home transitional care interventions on mortality and psychosocial outcomes in adults with heart failure: a meta-analysis	2021	Eur J Cardiovasc Nurs	18	0	zvab105	Li, Y et al	systematic review
The effectiveness of transitional care interventions for adult people with heart failure on patient-centered health outcomes: A systematic review and meta-analysis including dose-response relationship	2021	International journal of nursing studies	117	0	103902	Li, Y et al	systematic review
Effects of nurse-led transitional care interventions for patients with heart failure on healthcare utilization: A meta-analysis of randomized controlled trials	2021	PLoS One	16	12	E0261300	Li, Y et al	systematic review
The impact of nurse practitioners on health outcomes in outpatient heart failure management: a systematic review	2021	Canadian Journal of Cardiovascular Nursing	31	2	13-17	Fichadiya et al	systematic review
The impact of nurse-led community-based models of care on hospital admission rates in heart failure patients: An integrative review	2021	Heart Lung	50	5	685-692	Ledwin et al	systematic review

Table S2. ROBINS-I adaptation

Bias domain	Signaling questions	Description	Response option
Domain 1. Bias due to confounding (prognostic factors - thus related to the outcome- also related to intervention assignment)	1.1 Is there any reason to think that patients were "too much stable" during the period? or patients were too decompensate during the period?	The first question assesses the risk of the survivor, the second assesses the risk of the disease's own decline	Y/PY/PN/N
	1.4 If Y or PY to 1.1: The authors performed any specific analysis to mitigate that bias?		Y/PY/PN/N
	1.6. Did the authors control for any post-intervention variables that could have been affected by the intervention?	Controlling for post-intervention variables that are affected by intervention is not appropriate. Controlling for mediating variables estimates the direct effect of intervention and may introduce bias. Controlling for common effects of intervention and outcome introduces bias.	Y/PY/PN/N
			Risk of bias:
Domain 2. Bias in selection of participants into the study	2.1 Was selection of participants into the study (or into the analysis) based on participant characteristics observed after the start of intervention?	Inclusion criteria previously defined	Y/PY/PN/N
	2.4 Do start of follow-up and start of intervention coincides for most participants?	If participants are not followed from the start of the intervention then a period of follow up has been excluded, and individuals who experienced the outcome soon after intervention will be missing from analyses. This problem may occur when prevalent, rather than	Y/PY/PN/N

		new (incident), users of the intervention are included in analyses.	
	2.5 If N/PN to 2.4: Were adjustment techniques used that are likely to correct for the presence of selection biases?	It is in principle possible to correct for selection biases, for example by using inverse probability weights to create a pseudo-population in which the selection bias has been removed, or by modelling the distributions of the missing participants or follow up times and outcome events and including them using missing data methodology. However such methods are rarely used and the answer to this question will usually be "No".	Y/PY/PN/N
			Risk of bias:
Domain 3. Bias in classification of interventions	3.1 There was a previous clearly defined intervention?	Judge whether the intervention is sufficiently defined	Y/PY/PN/N
	3.2 The inclusion and exclusion criteria for participants were clearly defined?	Judge if inclusion and exclusion criteria are sufficiently defined	Y/PY/PN/N
	3.3 Could classification of intervention status have been affected by knowledge of the outcome or risk of the outcome?		Y/PY/PN/N
			Risk of bias:
Domain 4. Bias due to deviations from intended interventions	4.1 Were there deviations from the intended intervention beyond what would be expected in usual practice?	Deviations that happen in usual practice following the intervention (for example, cessation of a drug intervention because of acute toxicity) are part of the intended intervention and therefore do not lead to bias in the effect of assignment to intervention.	Y/PY/PN/N

	4.2 If Y/PY to 4.1: Were these deviations balanced in all the intervention group?	If deviations appeared, were homogeneous for all the intervention group?	Y/PY/PN/N
			Risk of bias:
Domain 5. Bias due to missing data	5.1 Were outcome data available for all, or nearly all, participants?	“Nearly all” should be interpreted as “enough to be confident of the findings”, and a suitable proportion depends on the context. In some situations, availability of data from 95% (or possibly 90%) of the participants may be sufficient, providing that events of interest are reasonably common in both intervention groups. One aspect of this is that review authors would ideally try and locate an analysis plan for the study.	Y/PY/PN/N
	5.2 Were participants excluded due to missing data on intervention status?	Missing intervention status may be a problem. This requires that the intended study sample is clear, which it may not be in practice.	Y/PY/PN/N
	5.3 Were participants excluded due to missing data on other variables needed for the analysis?	This question relates particularly to participants excluded from the analysis because of missing information on confounders that were controlled for in the analysis.	Y/PY/PN/N
	5.5 If PN/N to 5.1, or Y/PY to 5.2 or 5.3: Is there evidence that results were robust to the presence of missing data?	Evidence for robustness may come from how missing data were handled in the analysis and whether sensitivity analyses were performed by the investigators, or occasionally from additional analyses performed by the systematic reviewers. It is important to assess whether assumptions employed in analyses are clear and plausible. Both content knowledge and statistical expertise will often be required for this. For instance, use of a statistical method such as multiple	Y/PY/PN/N

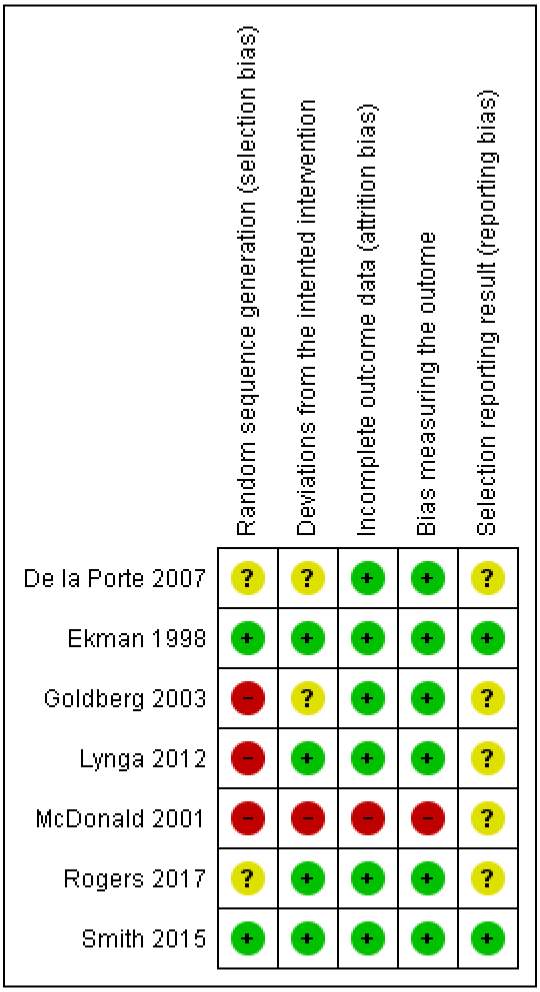
		imputation does not guarantee an appropriate answer. Review authors should seek naïve (complete-case) analyses for comparison, and clear differences between complete-case and multiple imputation-based findings should lead to careful assessment of the validity of the methods used.	
			Risk of bias:
Domain 6. Bias in measurement of outcomes	6.1 Could the outcome measure have been influenced by knowledge of the intervention received?	Some outcome measures involve negligible assessor judgment, e.g. all-cause mortality or non-repeatable automated laboratory assessments. Risk of bias due to measurement of these outcomes would be expected to be low.	Y/PY/PN/N
	6.2 Were outcome assessors aware of the intervention received by study participants?	If outcome assessors were blinded to intervention status, the answer to this question would be 'No'. In other situations, outcome assessors may be unaware of the interventions being received by participants despite there being no active blinding by the study investigators; the answer this question would then also be 'No'. In studies where participants report their outcomes themselves, for example in a questionnaire, the outcome assessor is the study participant. In an observational study, the answer to this question will usually be 'Yes' when the participants report their outcomes themselves.	Y/PY/PN/N
	6.3 Were comparable methods before and after the intervention?	Comparable assessment methods (i.e. data collection) would involve the same outcome detection methods and thresholds, same time point, same definition, and same measurements.	Y/PY/PN/N

	6.4 Were any systematic errors in measurement of the outcome related to intervention received?	This question refers to differential misclassification of outcomes. Systematic errors in measuring the outcome, if present, could cause bias if they are related to intervention or to a confounder of the intervention-outcome relationship. This will usually be due either to outcome assessors being aware of the intervention received or to non-comparability of outcome assessment methods, but there are examples of differential misclassification arising despite these controls being in place.	Y/PY/PN/N
			Risk of bias:
Domain 7. Bias in selection of the reported result	Is the reported effect estimate likely to be selected, on the basis of the results, from... 7.1. ... multiple outcome measurements within the outcome domain?	For a specified outcome domain, it is possible to generate multiple effect estimates for different measurements. If multiple measurements were made, but only one or a subset is reported, there is a risk of selective reporting on the basis of results.	Y/PY/PN/N
	7.2 ... multiple analyses of the intervention outcome relationship?	Because of the limitations of using data from non-randomized studies for analyses of effectiveness (need to control confounding, substantial missing data, etc), analysts may implement different analytic methods to address these limitations. Examples include unadjusted and adjusted models; use of final value vs change from baseline vs analysis of covariance; different transformations of variables; a continuously scaled outcome converted to categorical data with different cut-points; different sets of covariates used for adjustment; and different analytic strategies for dealing with missing data. Application of such methods	Y/PY/PN/N

		generates multiple estimates of the effect of the intervention versus the comparator on the outcome. If the analyst does not pre-specify the methods to be applied, and multiple estimates are generated but only one or a subset is reported, there is a risk of selective reporting on the basis of results.	
	7.3 ... different subgroups?	Particularly with large cohorts often available from routine data sources, it is possible to generate multiple effect estimates for different subgroups or simply to omit varying proportions of the original cohort. If multiple estimates are generated but only one or a subset is reported, there is a risk of selective reporting on the basis of results.	Y/PY/PN/N
			Risk of bias:

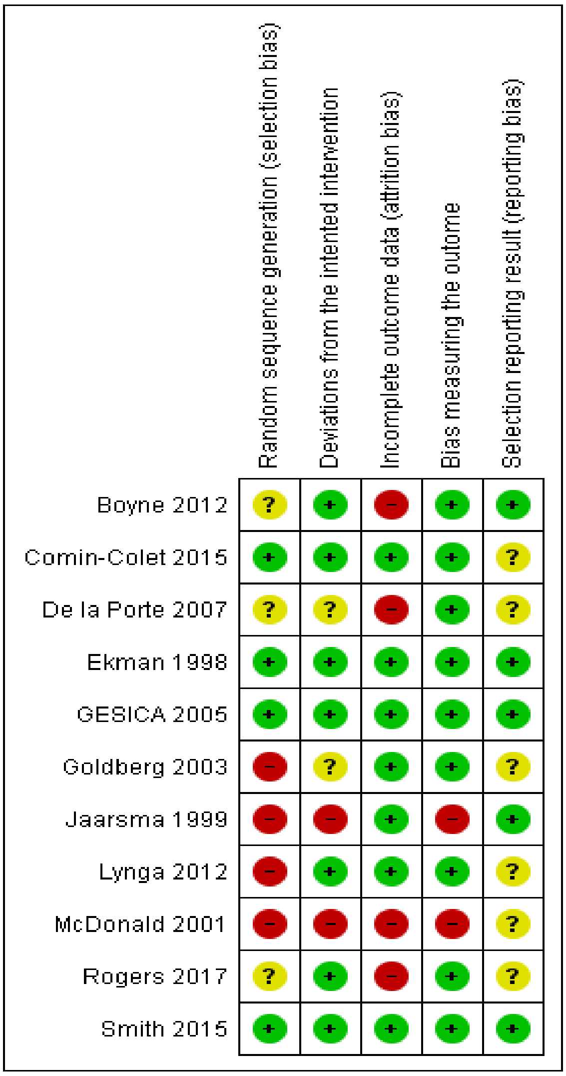
Table S3. Assessment of Risk of bias (RoB) in Randomized controlled trial studies.

Outcome assessment: All-cause mortality



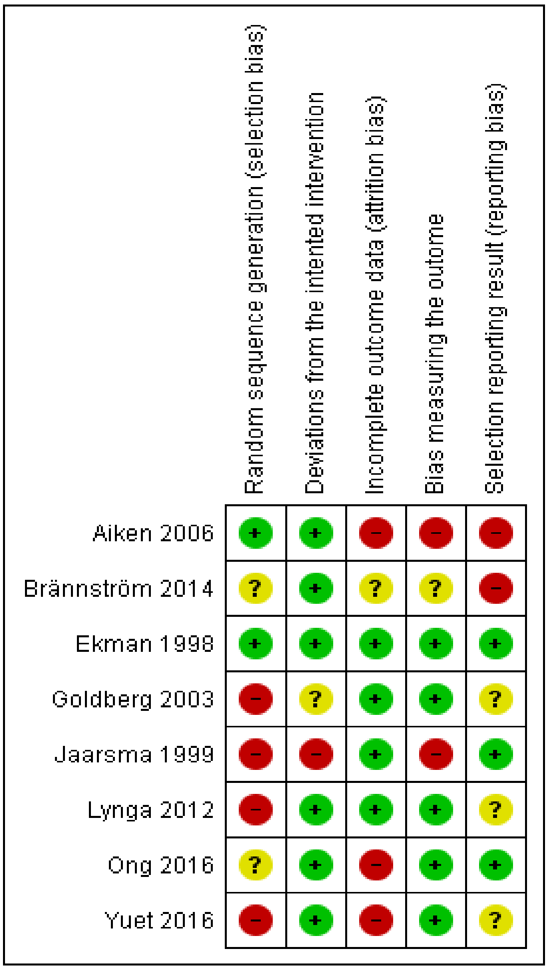
	Random sequence generation (selection bias)	Deviations from the intented intervention	Incomplete outcome data (attrition bias)	Bias measuring the outome	Selection reporting result (reporting bias)
De la Porte 2007	?	?	+	+	?
Ekman 1998	+	+	+	+	+
Goldberg 2003	−	?	+	+	?
Lynga 2012	−	+	+	+	?
McDonald 2001	−	−	−	−	?
Rogers 2017	?	+	+	+	?
Smith 2015	+	+	+	+	+

Outcome assessment: Hospitalizations for heart failure



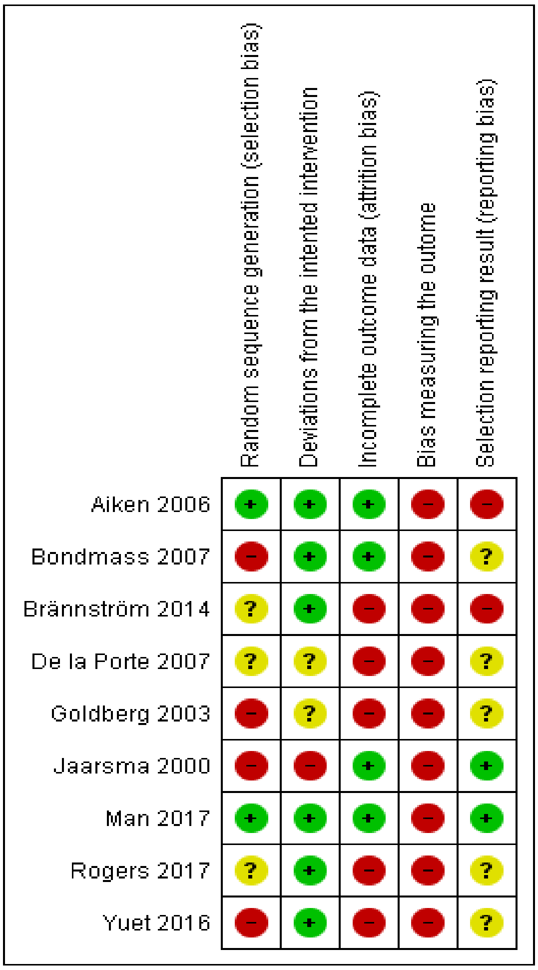
	Random sequence generation (selection bias)	Deviations from the intented intervention	Incomplete outcome data (attrition bias)	Bias measuring the outome	Selection reporting result (reporting bias)
Boyne 2012	?	+	−	+	+
Comin-Colet 2015	+	+	+	+	?
De la Porte 2007	?	?	−	+	?
Ekman 1998	+	+	+	+	+
GESICA 2005	+	+	+	+	+
Goldberg 2003	−	?	+	+	?
Jaarsma 1999	−	−	+	−	+
Lynga 2012	−	+	+	+	?
McDonald 2001	−	−	−	−	?
Rogers 2017	?	+	−	+	?
Smith 2015	+	+	+	+	+

Outcome assessment: All-cause hospitalizations



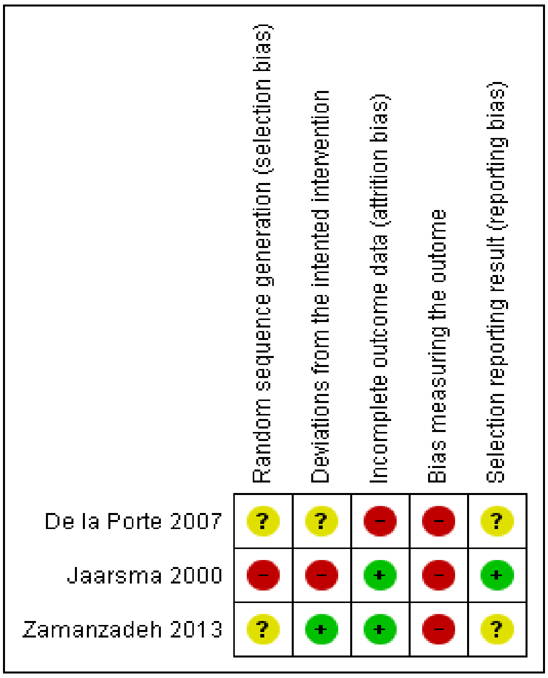
	Random sequence generation (selection bias)	Deviations from the intented intervention	Incomplete outcome data (attrition bias)	Bias measuring the outome	Selection reporting result (reporting bias)
Aiken 2006	+	+	−	−	−
Brännström 2014	?	+	?	?	−
Ekman 1998	+	+	+	+	+
Goldberg 2003	−	?	+	+	?
Jaarsma 1999	−	−	+	−	+
Lynga 2012	−	+	+	+	?
Ong 2016	?	+	−	+	+
Yuet 2016	−	+	−	+	?

Outcome assessment: Quality of life



	Random sequence generation (selection bias)	Deviations from the intented intervention	Incomplete outcome data (attrition bias)	Bias measuring the outome	Selection reporting result (reporting bias)
Aiken 2006	+	+	+	−	−
Bondmass 2007	−	+	+	−	?
Brännström 2014	?	+	−	−	−
De la Porte 2007	?	?	−	−	?
Goldberg 2003	−	?	−	−	?
Jaarsma 2000	−	−	+	−	+
Man 2017	+	+	+	−	+
Rogers 2017	?	+	−	−	?
Yuet 2016	−	+	−	−	?

Outcome assessment: Self-care



	Random sequence generation (selection bias)	Deviations from the intented intervention	Incomplete outcome data (attrition bias)	Bias measuring the outome	Selection reporting result (reporting bias)
De la Porte 2007	?	?	−	−	?
Jaarsma 2000	−	−	+	−	+
Zamanzadeh 2013	?	+	+	−	?

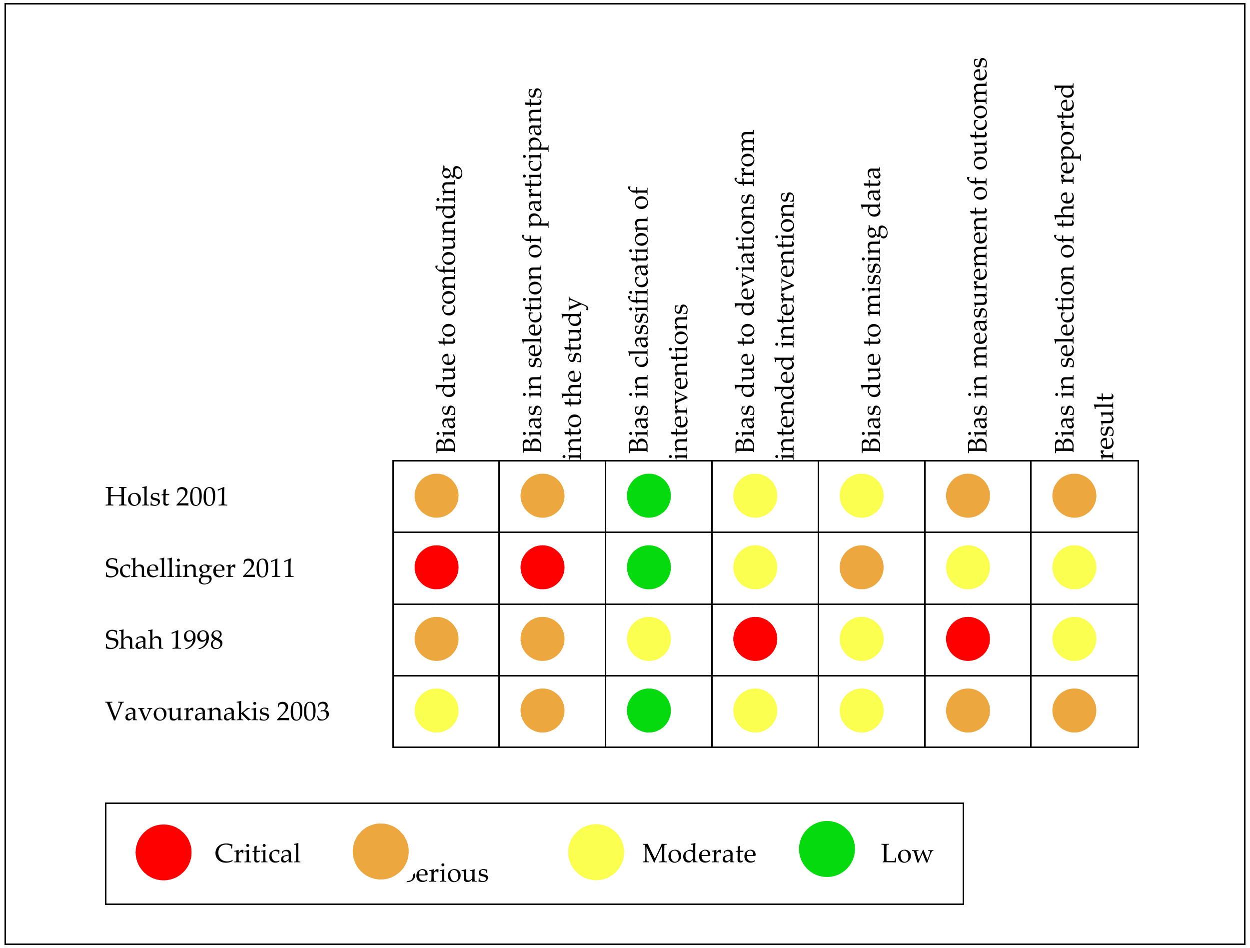
Table S4. Assessment of Risk of bias with adaptation ROBINS-I tool in non-Randomized controlled trial studies.

Outcome assessment: Hospitalizations for heart failure

	Bias due to confounding	Bias in selection of participants into the study	Bias in classification of interventions	Bias due to deviations from intended	Bias due to missing data	Bias in measurement of outcomes	Bias in selection of the reported result
Delaney 2010	🟡	🟡	🟢	🟡	🟢	🟡	🟢
Fonarow 1997	🟢	🟢	🟢	🟢	🟡	🟢	🟡

🔴	Critical	🟠	Serious	🟡	Moderate	🟢	Low

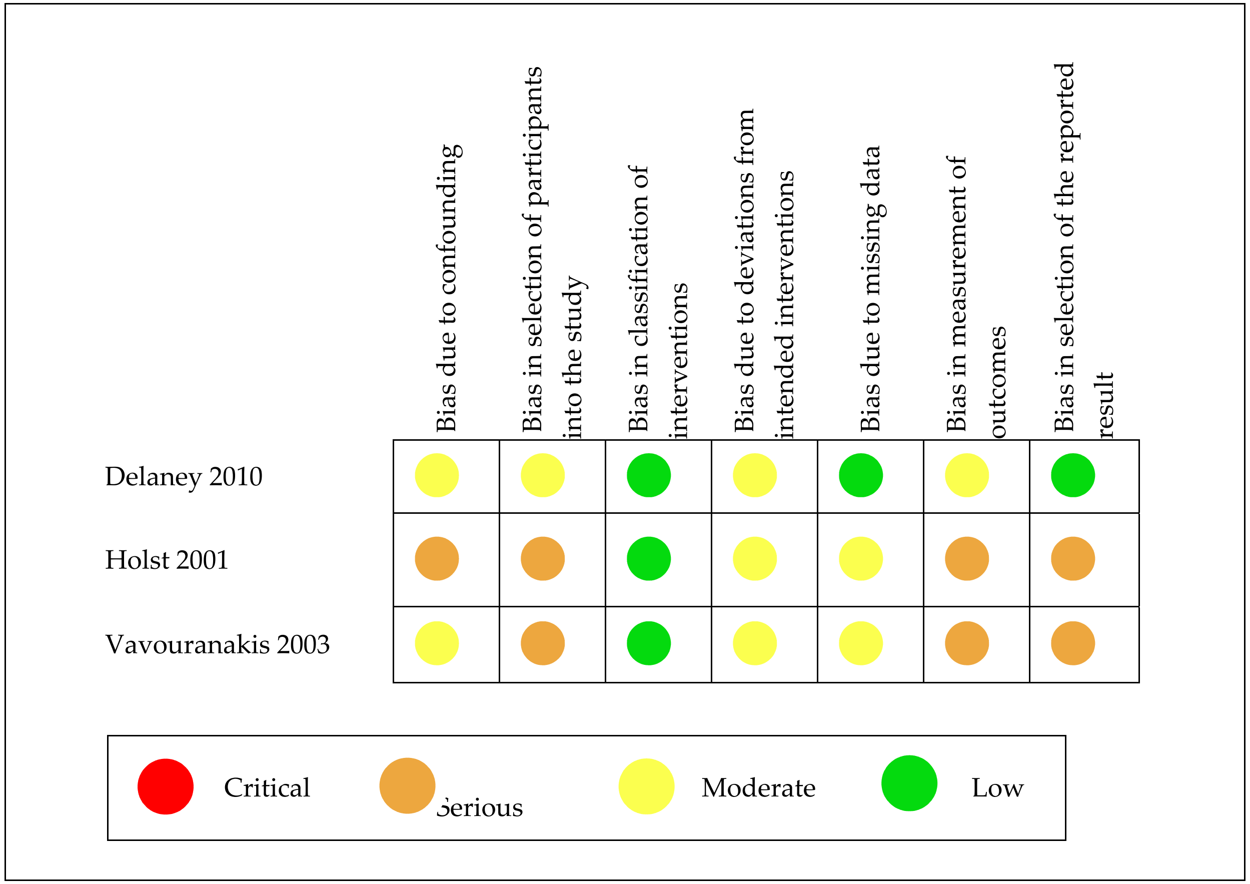
Outcome assessment: All-cause hospitalizations



	Bias due to confounding	Bias in selection of participants into the study	Bias in classification of interventions	Bias due to deviations from intended interventions	Bias due to missing data	Bias in measurement of outcomes	Bias in selection of the reported result
Holst 2001	🟠	🟠	🟢	🟡	🟡	🟠	🟠
Schellinger 2011	🔴	🔴	🟢	🟡	🟠	🟡	🟡
Shah 1998	🟠	🟠	🟡	🔴	🟡	🔴	🟡
Vavouranakis 2003	🟡	🟠	🟢	🟡	🟡	🟠	🟠

🔴 Critical 🟠 Serious 🟡 Moderate 🟢 Low

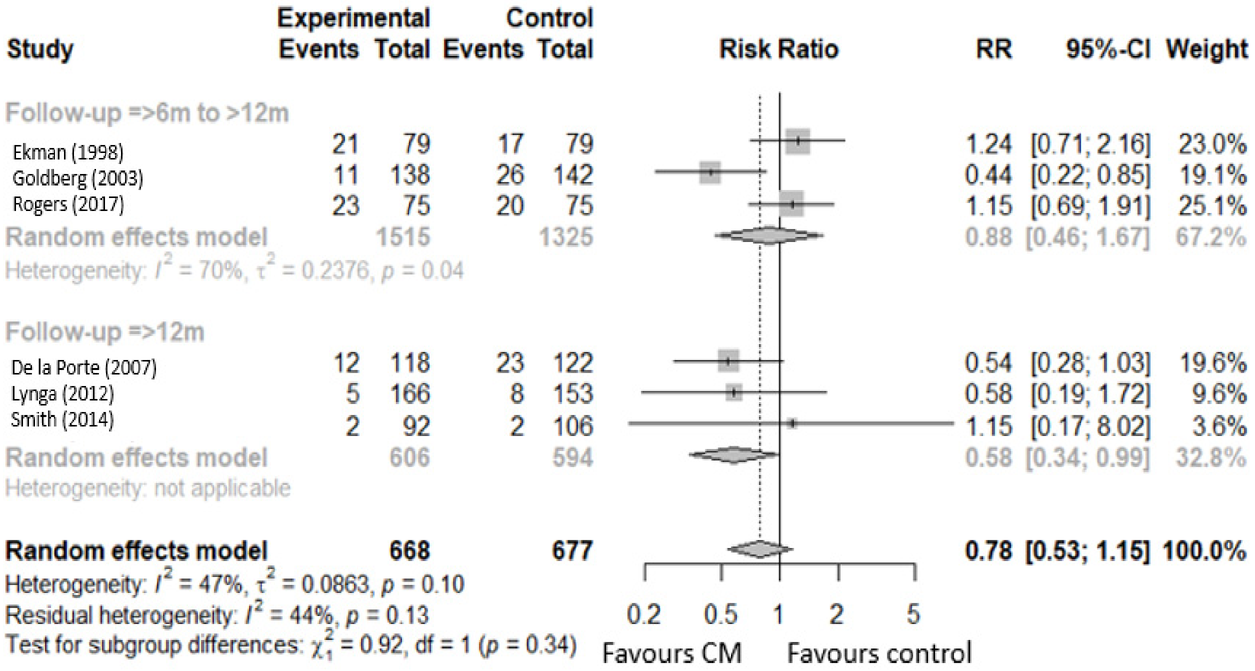
Outcome assessment: Quality of life



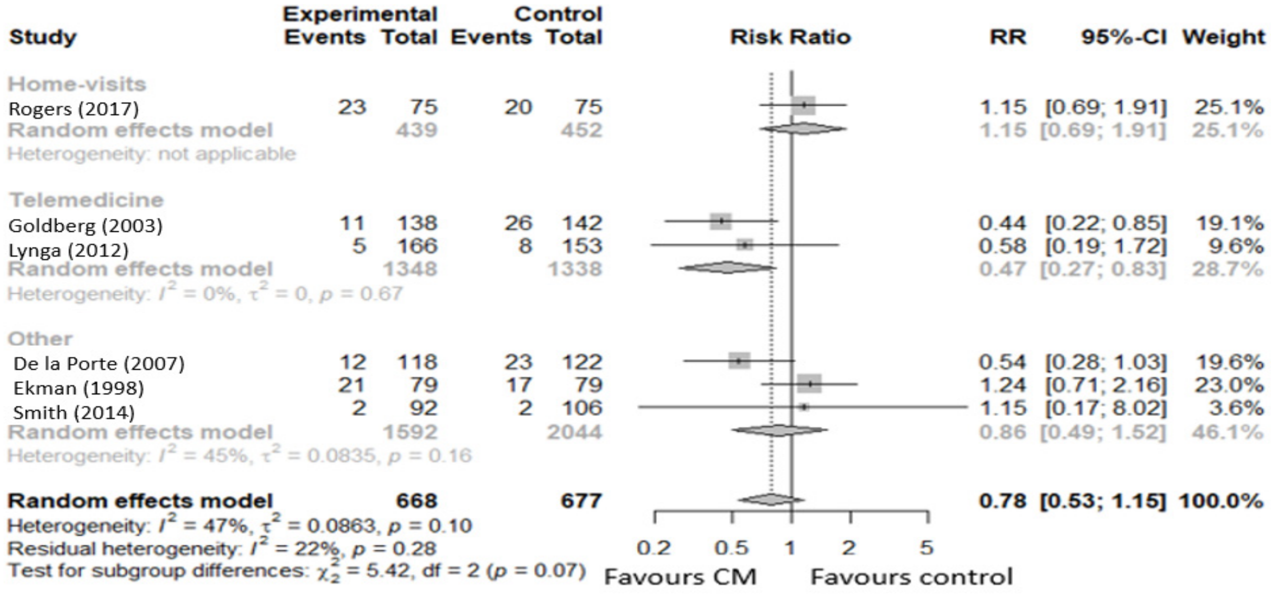
	Bias due to confounding	Bias in selection of participants into the study	Bias in classification of interventions	Bias due to deviations from intended interventions	Bias due to missing data	Bias in measurement of outcomes	Bias in selection of the reported result
Delaney 2010	🟡	🟡	🟢	🟡	🟢	🟡	🟢
Holst 2001	🟠	🟠	🟢	🟡	🟡	🟠	🟠
Vavouranakis 2003	🟡	🟠	🟢	🟡	🟡	🟠	🟠

🔴 Critical 🟠 Serious 🟡 Moderate 🟢 Low

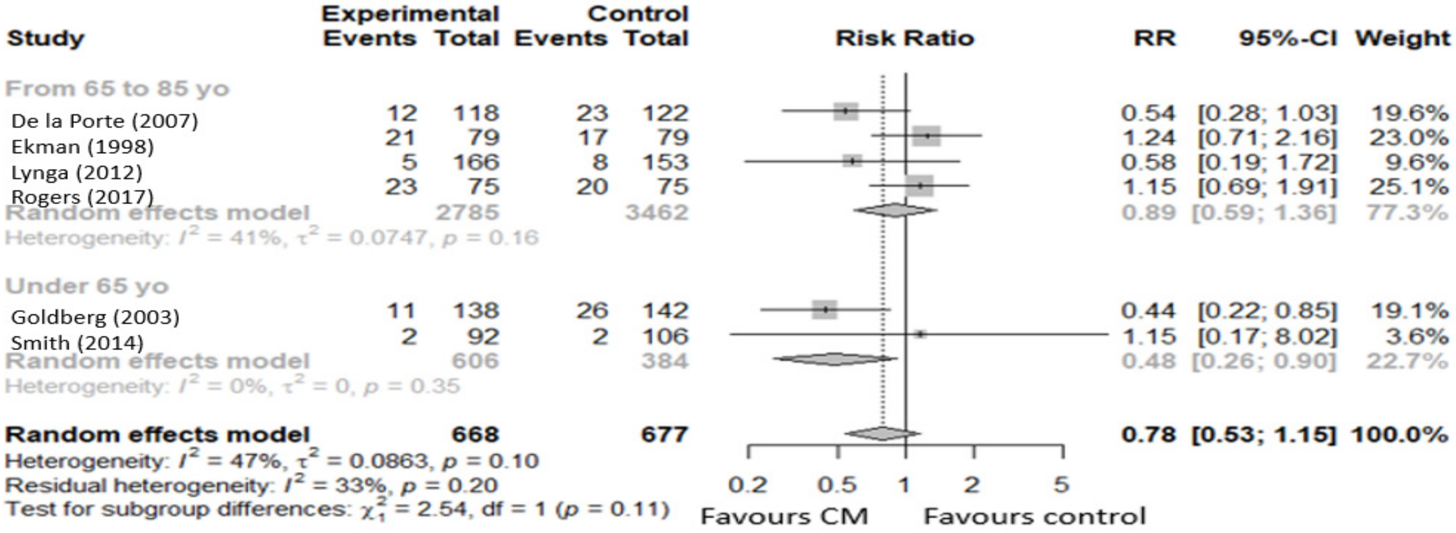
Figure S1. Meta-analysis of subgroups according follow-up time, type of nurse-led case management delivered and age.

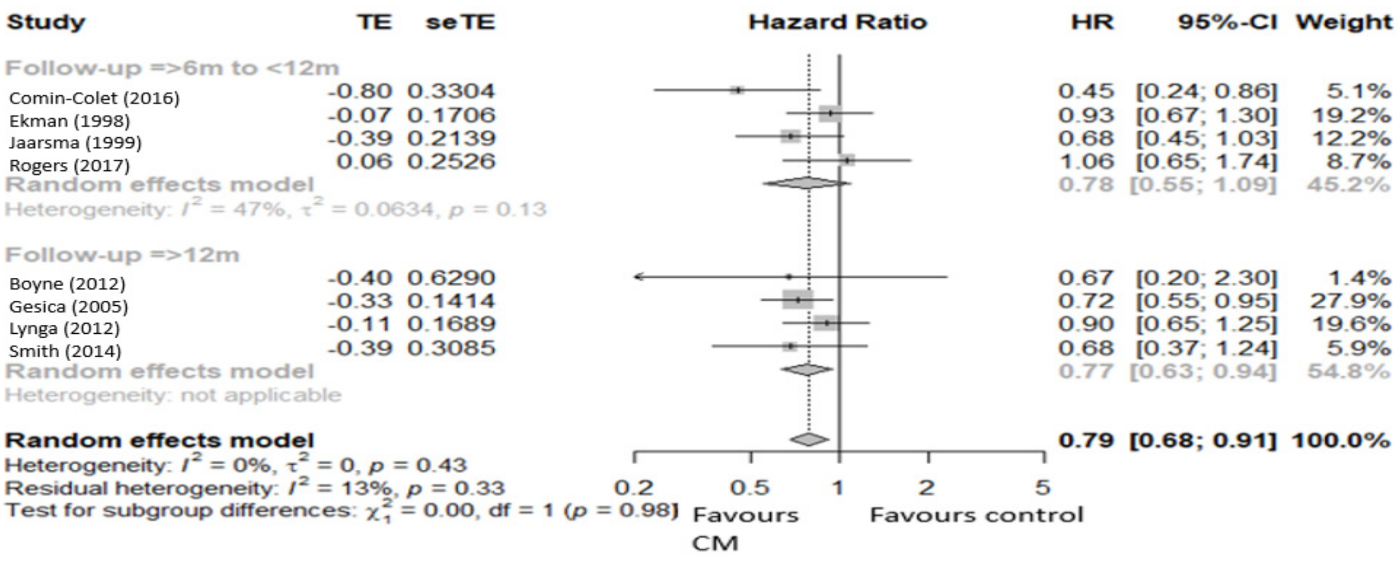
All-cause mortality	Follow-up subgroup analysis 

Type of nurse-led case management delivered subgroup analysis

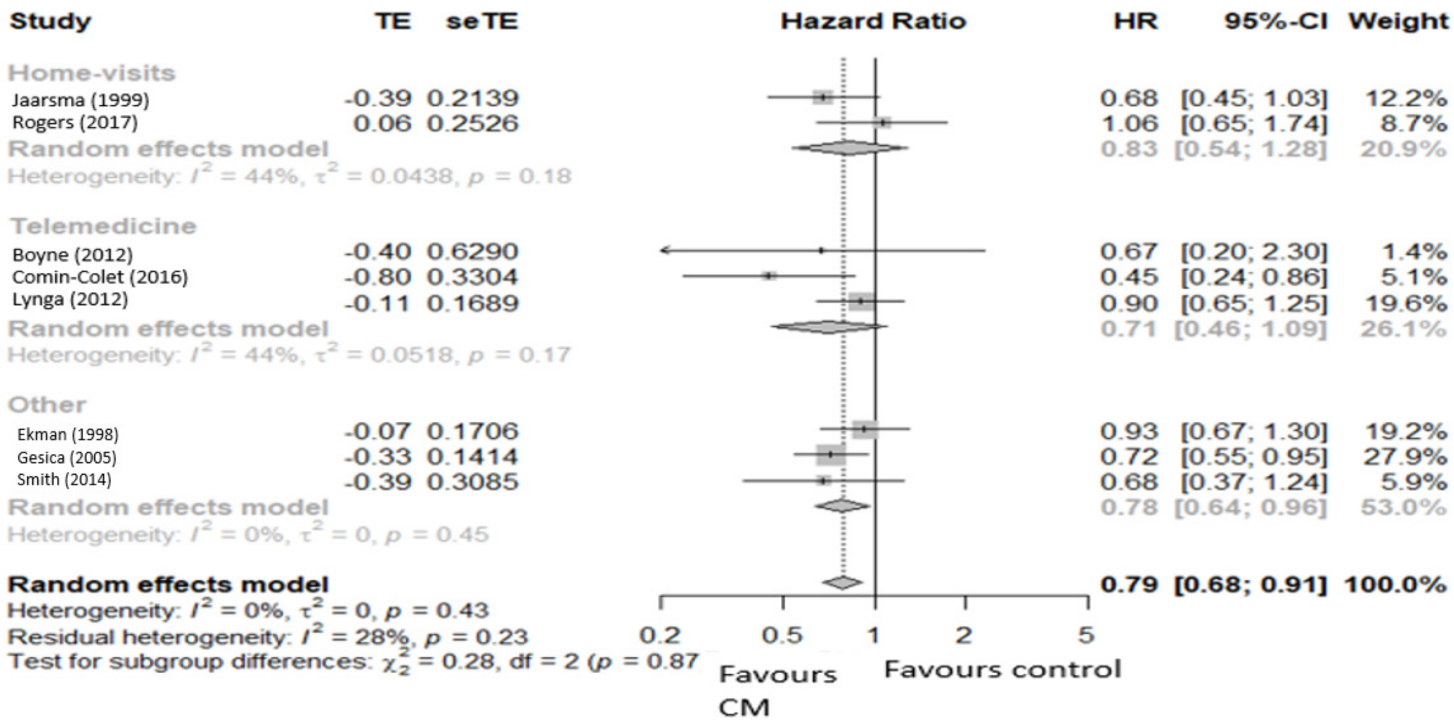


Age subgroup analysis

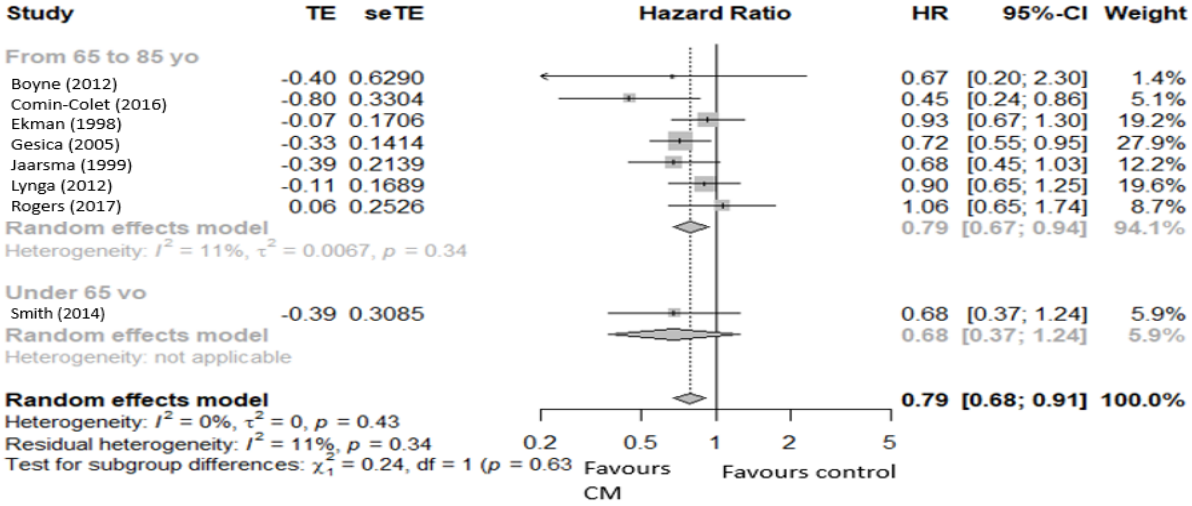


Hospitalizations for heart failure	Follow-up subgroup analysis 

Type of nurse-led case management delivered subgroup analysis



Age subgroup analysis

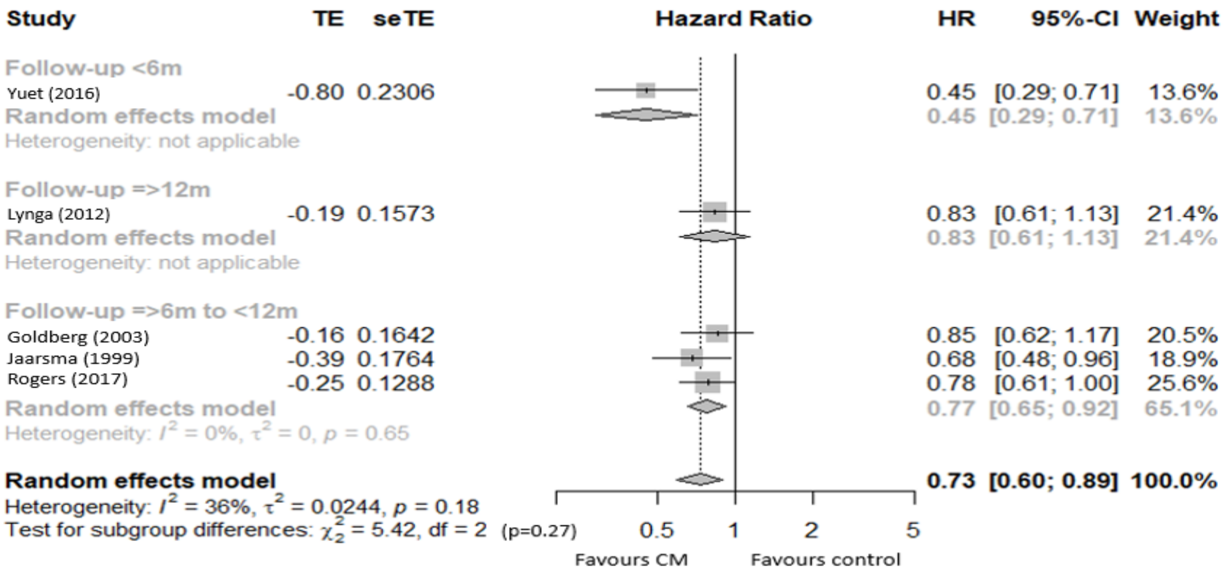


Study	TE	seTE	HR	95%-CI	Weight
From 65 to 85 yo					
Boyne (2012)	-0.40	0.6290	0.67	[0.20; 2.30]	1.4%
Comin-Colet (2016)	-0.80	0.3304	0.45	[0.24; 0.86]	5.1%
Ekman (1998)	-0.07	0.1706	0.93	[0.67; 1.30]	19.2%
Gesica (2005)	-0.33	0.1414	0.72	[0.55; 0.95]	27.9%
Jaarsma (1999)	-0.39	0.2139	0.68	[0.45; 1.03]	12.2%
Lynga (2012)	-0.11	0.1689	0.90	[0.65; 1.25]	19.6%
Rogers (2017)	0.06	0.2526	1.06	[0.65; 1.74]	8.7%
Random effects model			0.79	[0.67; 0.94]	94.1%
Heterogeneity: I^2 = 11%, τ^2 = 0.0067, p = 0.34					
Under 65 vo					
Smith (2014)	-0.39	0.3085	0.68	[0.37; 1.24]	5.9%
Random effects model			0.68	[0.37; 1.24]	5.9%
Heterogeneity: not applicable					
Random effects model			**0.79**	**[0.68; 0.91]**	**100.0%**

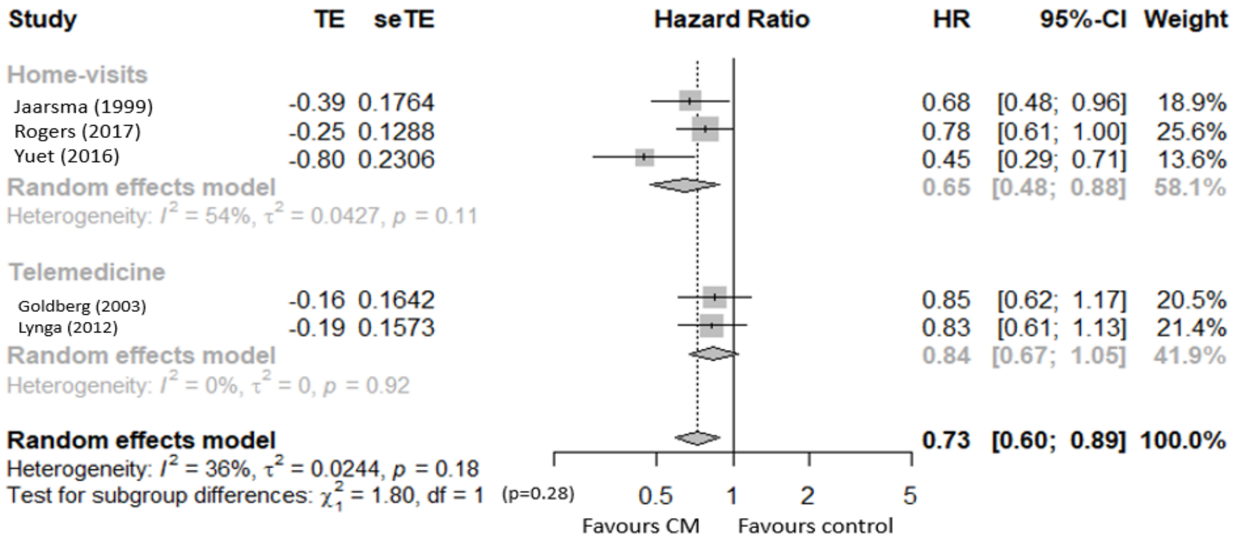
Heterogeneity: I^2 = 0%, τ^2 = 0, p = 0.43

Residual heterogeneity: I^2 = 11%, p = 0.34

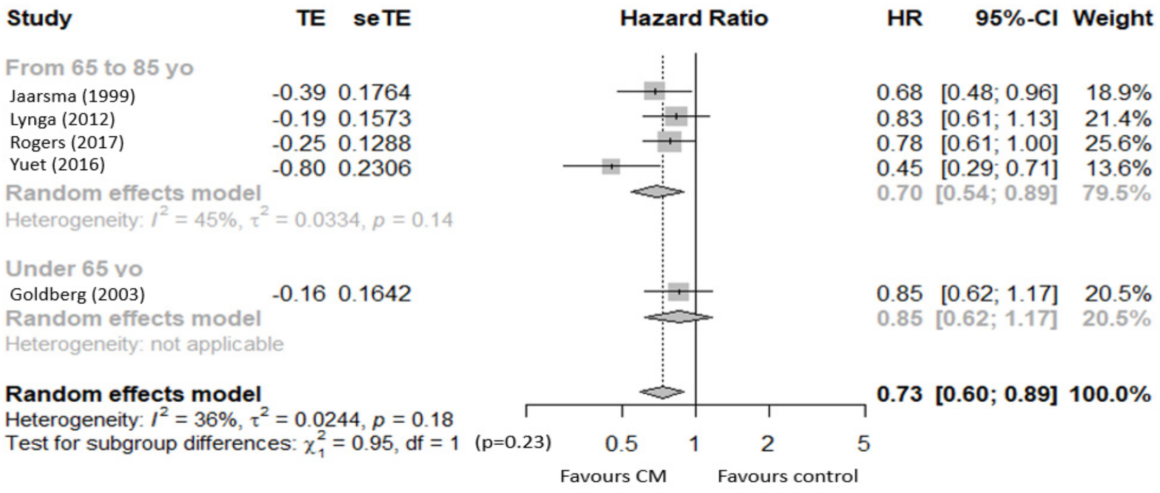
Test for subgroup differences: χ^2_1 = 0.24, df = 1 (p = 0.63

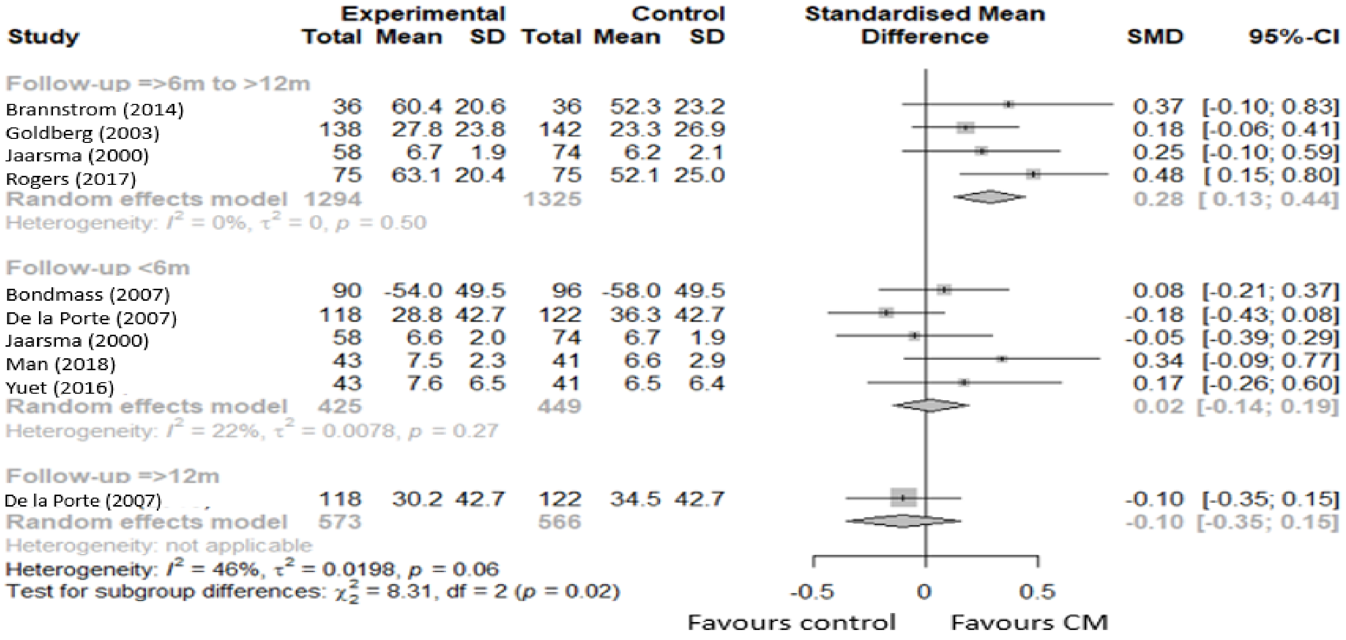
All-cause hospitalizations	Follow-up subgroup analysis 

Type of nurse-led case management delivered subgroup analysis

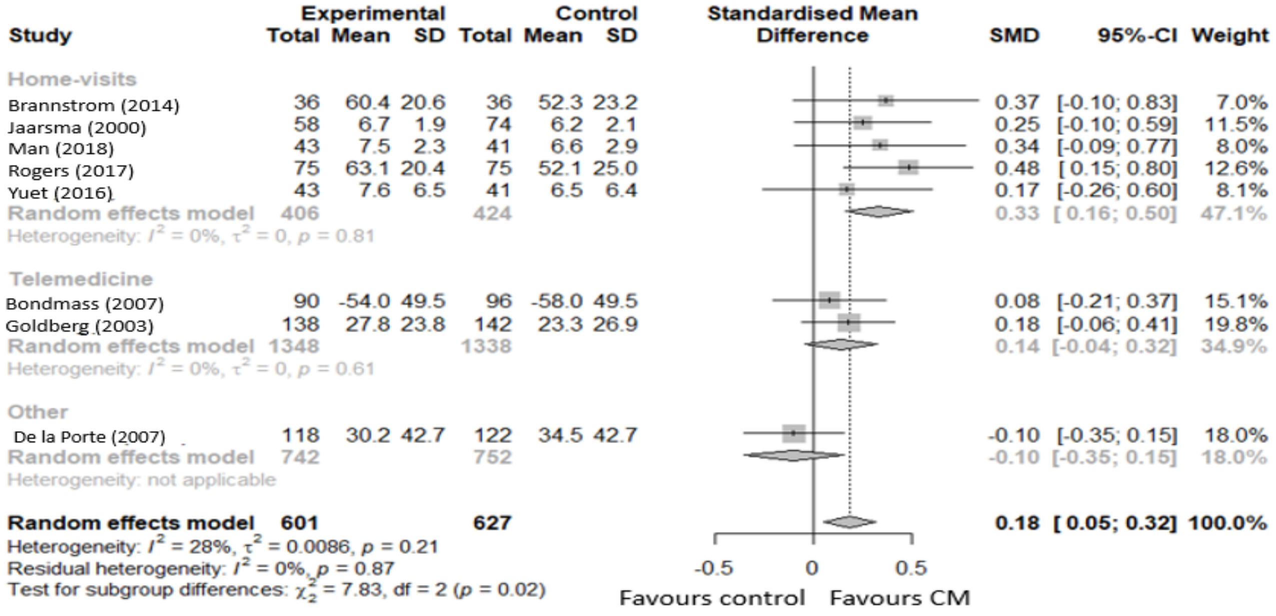


Age subgroup analysis



Quality of life	Follow-up subgroup analysis 

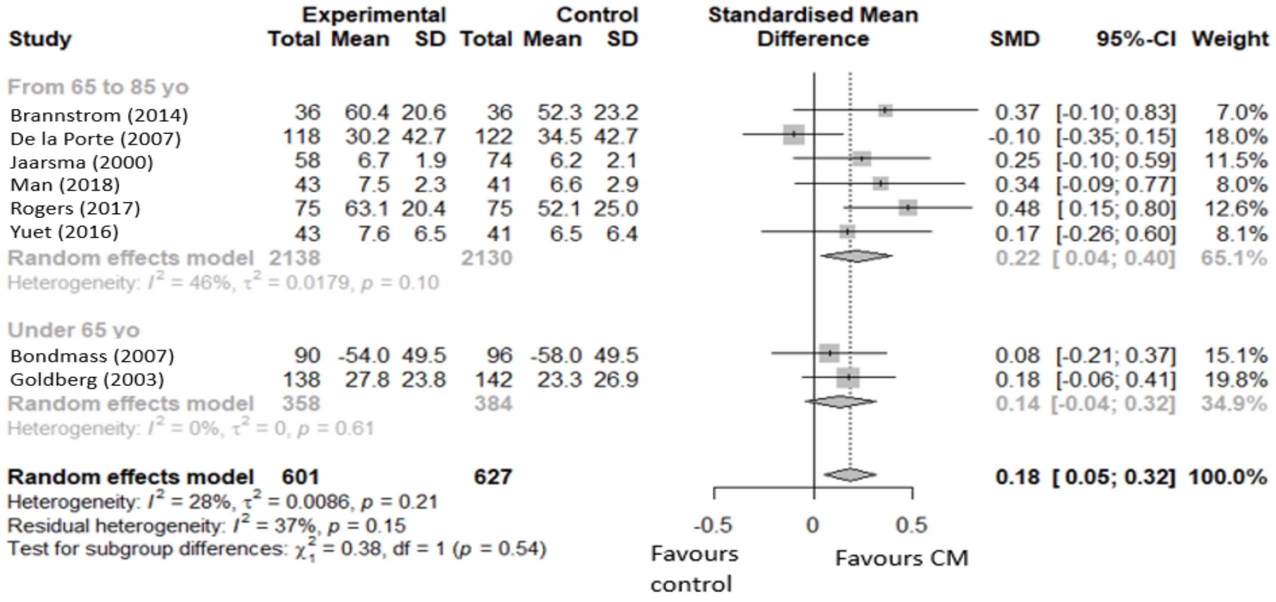
Type of nurse-led case management delivered subgroup analysis



Study	Experimental Total	Experimental Mean	Experimental SD	Control Total	Control Mean	Control SD	SMD	95%-CI	Weight
Home-visits									
Brannstrom (2014)	36	60.4	20.6	36	52.3	23.2	0.37	[-0.10; 0.83]	7.0%
Jaarsma (2000)	58	6.7	1.9	74	6.2	2.1	0.25	[-0.10; 0.59]	11.5%
Man (2018)	43	7.5	2.3	41	6.6	2.9	0.34	[-0.09; 0.77]	8.0%
Rogers (2017)	75	63.1	20.4	75	52.1	25.0	0.48	[0.15; 0.80]	12.6%
Yuet (2016)	43	7.6	6.5	41	6.5	6.4	0.17	[-0.26; 0.60]	8.1%
Random effects model	406			424			0.33	[0.16; 0.50]	47.1%
Heterogeneity: $I^2 = 0\%$, $\tau^2 = 0$, $p = 0.81$									
Telemedicine									
Bondmass (2007)	90	-54.0	49.5	96	-58.0	49.5	0.08	[-0.21; 0.37]	15.1%
Goldberg (2003)	138	27.8	23.8	142	23.3	26.9	0.18	[-0.06; 0.41]	19.8%
Random effects model	1348			1338			0.14	[-0.04; 0.32]	34.9%
Heterogeneity: $I^2 = 0\%$, $\tau^2 = 0$, $p = 0.61$									
Other									
De la Porte (2007)	118	30.2	42.7	122	34.5	42.7	-0.10	[-0.35; 0.15]	18.0%
Random effects model	742			752			-0.10	[-0.35; 0.15]	18.0%
Heterogeneity: not applicable									
Random effects model	**601**			**627**			**0.18**	**[0.05; 0.32]**	**100.0%**

Heterogeneity: $I^2 = 28\%$, $\tau^2 = 0.0086$, $p = 0.21$
Residual heterogeneity: $I^2 = 0\%$, $p = 0.87$
Test for subgroup differences: $\chi^2_2 = 7.83$, df = 2 ($p = 0.02$)

Age subgroup analysis

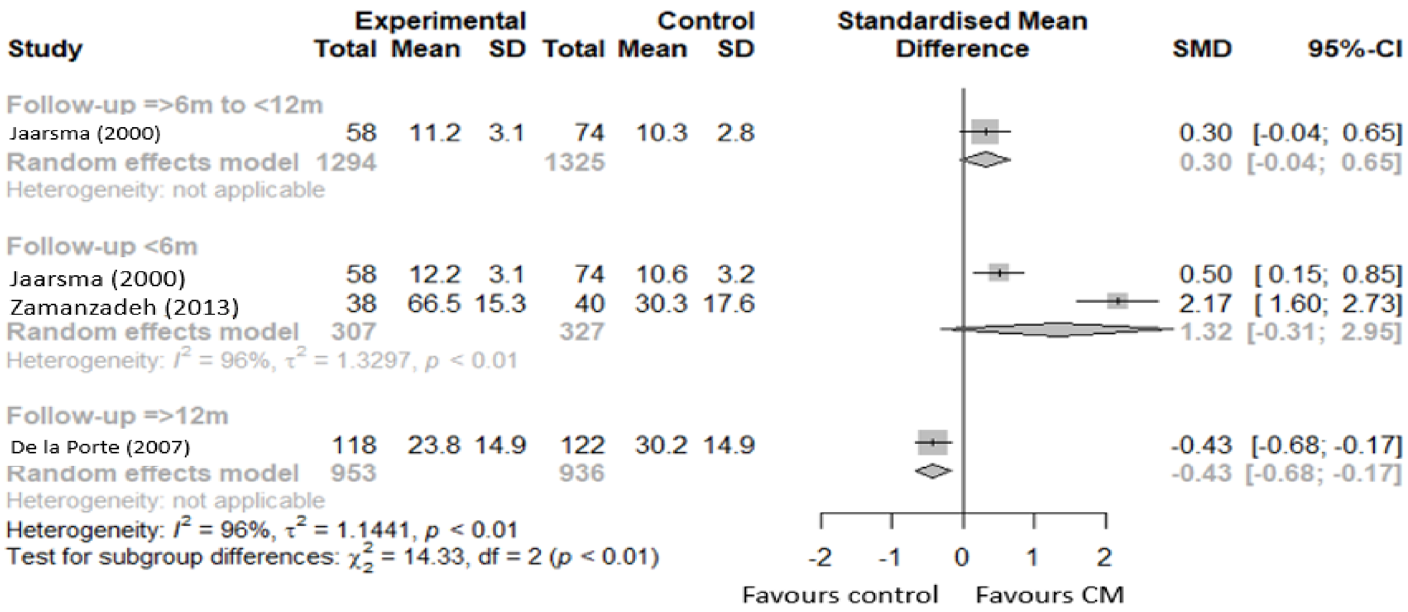


Study	Experimental Total	Experimental Mean	Experimental SD	Control Total	Control Mean	Control SD	SMD	95%-CI	Weight
From 65 to 85 yo									
Brannstrom (2014)	36	60.4	20.6	36	52.3	23.2	0.37	[-0.10; 0.83]	7.0%
De la Porte (2007)	118	30.2	42.7	122	34.5	42.7	-0.10	[-0.35; 0.15]	18.0%
Jaarsma (2000)	58	6.7	1.9	74	6.2	2.1	0.25	[-0.10; 0.59]	11.5%
Man (2018)	43	7.5	2.3	41	6.6	2.9	0.34	[-0.09; 0.77]	8.0%
Rogers (2017)	75	63.1	20.4	75	52.1	25.0	0.48	[0.15; 0.80]	12.6%
Yuet (2016)	43	7.6	6.5	41	6.5	6.4	0.17	[-0.26; 0.60]	8.1%
Random effects model	2138			2130			0.22	[0.04; 0.40]	65.1%
Heterogeneity: $I^2 = 46\%$, $\tau^2 = 0.0179$, $p = 0.10$									
Under 65 yo									
Bondmass (2007)	90	-54.0	49.5	96	-58.0	49.5	0.08	[-0.21; 0.37]	15.1%
Goldberg (2003)	138	27.8	23.8	142	23.3	26.9	0.18	[-0.06; 0.41]	19.8%
Random effects model	358			384			0.14	[-0.04; 0.32]	34.9%
Heterogeneity: $I^2 = 0\%$, $\tau^2 = 0$, $p = 0.61$									
Random effects model	**601**			**627**			**0.18**	**[0.05; 0.32]**	**100.0%**

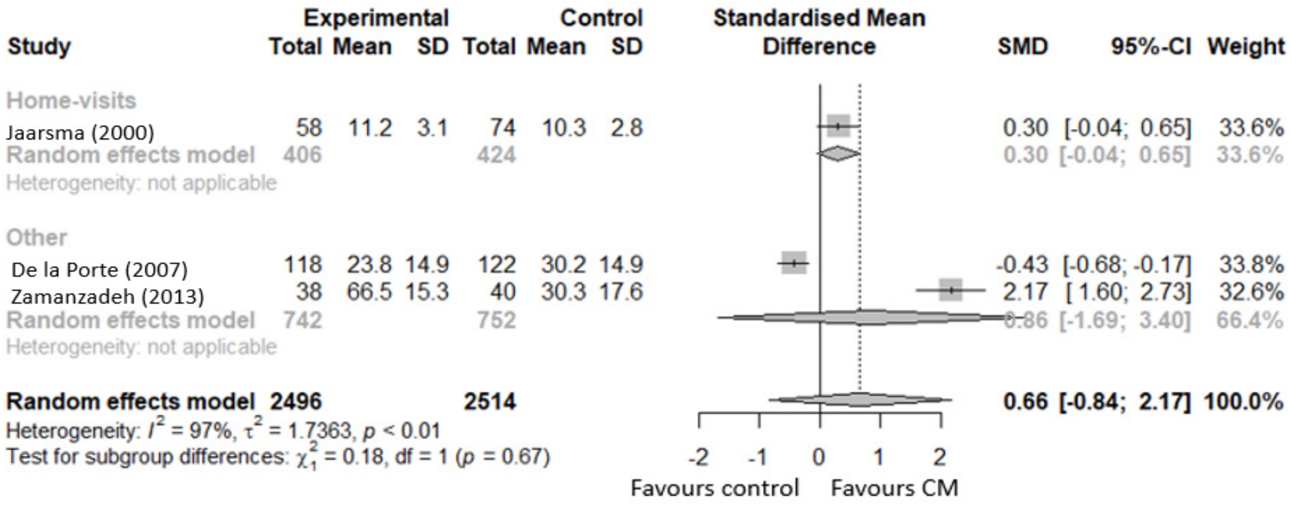
Heterogeneity: $I^2 = 28\%$, $\tau^2 = 0.0086$, $p = 0.21$

Residual heterogeneity: $I^2 = 37\%$, $p = 0.15$

Test for subgroup differences: $\chi^2_1 = 0.38$, df = 1 ($p = 0.54$)

Self-care	Follow-up subgroup analysis 

Type of nurse-led case management delivered subgroup analysis



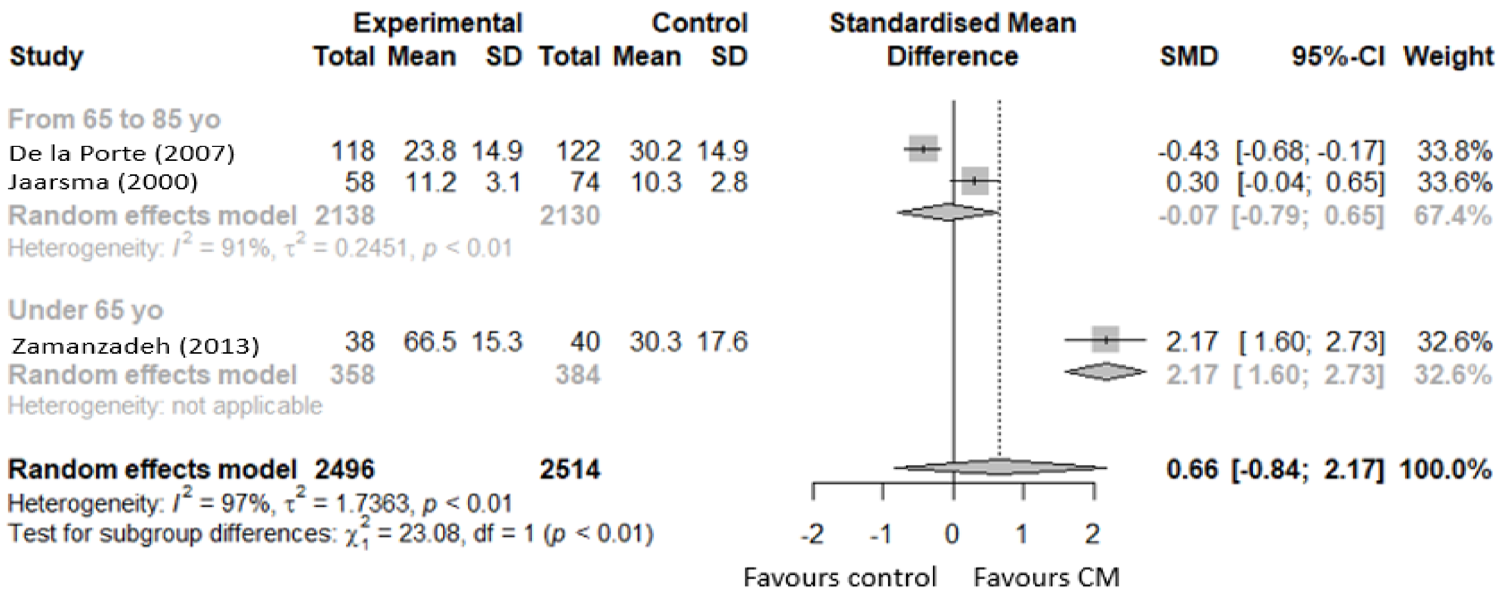
	Age subgroup analysis 

Table S5. Descriptive tables of studies with incomplete outcome data.

Hospitalizations for heart failure					
Author, year	**Case management (CM)**	**Number of subjects in CM group**	**Control group**	**Number of subjects in control group**	**Type of outcome reported**
De la Porte, 2015	23	118	47	122	Hospitalisations for HF and or death
Delaney, 2010	2	12	3	12	Number of events
Golberg, 2003	0.08	138	0.11	142	Average utilization
McDonald, 2001	0	35	0	35	Number of events
Fonarow, 1997	34	179	344	179	Number of events

All-cause hospitalizations					
Author, year	**Case management (Standard deviation)**	**Number of subjects in CM group**	**Control group**	**Number of subjects in control group**	**Type of outcome reported**
Brannstrom, 2014	15	36	53	36	Number of events
Holst, 2001	0.08 (0.28)	NI	1.05 (0.98)	NI	Average utilization
Vavouranakis, 2003	2.14 (NI)	33	1.25	28	Average utilization
Ekman, 1998	1.1 (1.3)	79	1.2 (1.5)	79	Average utilization
ONG, 2016	248	NI	223	NI	Number of events
Schellinger, 2011	34.9%	63	31.5%	715	Percentage of readmitted subjects
Shah, 1998	0.5 (NI)	17	1.2 (NI)	17	Average utilization

CM: Case management

Quality of life			
Author, year	**Questionnarie**	**Case Management (standard deviation)**	**Control group (standard deviation)**
Aiken, 2006	SF-36	0.16 (NI)	-0,17 (NI)
Delaney, 2010	MLHF	42.5 (17.9)	58.0 (17)
Holst, 2001	MLHF	32 (NI)	53 (NI)
Vavouranakis, 2003	MLHF	2.68 (0.034)	2.33 (0.032)

SF-36: Short Form-36 Health Survey **MLHF**: Minnesota living with heart failure

8. DISCUSSIÓ

8.1 TROBALLES PRINCIPALS

Els resultats dels 3 articles publicats en relació a aquesta tesi, responen a l'objectiu principal d'aprofundir en el coneixement sobre el final de vida dels pacients amb insuficiència cardíaca avançada. Aquests estudis, exploren quin paper té el context social en la mortalitat dels pacients, com és la vivència d'aquests en el seu dia a dia, i analitza l'efectivitat i la cost-efectivitat del programa de gestió de casos liderat per infermeres.

Les principals troballes dels resultats de la recerca són:

8.1.1 Context social i mortalitat

- Els pacients amb insuficiència cardíaca avançada amb un perfil social desfavorable tenen un major risc de mortalitat.
- Altres variables relacionades amb la mortalitat són el sexe masculí i tenir una alta dependència en les activitats bàsiques de la vida diària.

8.1.2 Vivència dels pacients amb IC avançada

- Els pacients descriuen que la informació respecte la malaltia és insuficient i contradictòria i la majoria refereix que el diagnòstic l'han rebut durant una exacerbació a urgències hospitalàries.
- Existeixen diferencies de gènere en la representació emocional de la malaltia. Les dones es consideren un pilar principal en la família i el fet de sentir la limitació física secundària a la IC té una repercussió emocional negativa.
- Els participants perceben el locus de control com a extern i es consideren incapaços d'evitar la progressió de la malaltia.
- El suport social és crucial per viure amb la IC.

8.1.3 Efectivitat i cost-efectivitat de la gestió de casos liderada per infermeres en els pacients amb IC avançada

- La gestió de casos dirigida per infermeres pot reduir els ingressos hospitalaris per totes les causes i els reingressos per IC.
- La qualitat de vida pot millorar amb la intervenció a mitjà termini. Es va trobar una millor autocura i supervivència en el grup de pacients en seguiment per la gestió de casos, tot i que no va ser estadísticament significatiu.
- En relació als costos associats, existeix una gran varietat entre estudis que van des dels 4.975$ fins als 27.538€. Un estudi va mostrar un bon perfil de cost-efectivitat sota una disponibilitat a pagar de 15.000€/AVAQ (costos del 2015). Aquest perfil podria correspondre a un model cost-efectiu al nostre entorn amb un llindar de cost per AVAQ <20.000€ [112].

8.2 DISCUSSIÓ CONJUNTA DELS ARTICLES

La discussió d'aquesta tesi s'articula en base als objectius principals de la mateixa. La discussió específica de cadascun dels articles es troba a les mateixes publicacions, on també es descriuen les limitacions i fortaleses de cada estudi.

L'estudi dels factors predictors de mortalitat de les persones amb IC avançada posa de manifest la relació de la mortalitat amb el resultat "problema social" de l'escala sòcio-familiar de Gijón. En la cohort analitzada, la majoria dels participants tenien risc social (63,6%), vivien sols o amb persones físicament dependents i els ingressos econòmics eren baixos. Aquests resultats contrasten amb els de la població general, on el risc social és menor [113]. Probablement la població d'IC avançada es troba molt més a risc degut al propi declivi de la malaltia, comorbiditats associades i dependència. És important destacar aquesta gravetat respecte la població general ja que, existeixen clares diferències i incloure la valoració social amb l'escala sòcio-familiar de Gijón dins els programes d'atenció [61], aportaria una visió més acurada sobre el pronòstic de la malaltia.

L'escala de Gijón es troba disponible al programa d'Estació Clínica d'Atenció Primària (ECAP) que es fa servir a la gran majoria dels centres d'atenció primària a Catalunya [114] i el resultat d'aquesta, podria ajudar a predir el pronòstic.
A més, tot i que és conegut que l'adherència al tractament dels pacients amb IC vers la presa de fàrmacs és generalment bona, algunes recomanacions com la de realitzar exercici regular formen part de les recomanacions amb més baixa adherència [115].

En aquest sentit, durant les entrevistes en profunditat a persones amb IC, els pacients van destacar que els professionals sanitaris donaven algunes recomanacions generals per a l'autocura que no eren possibles d'acomplir degut a l'estat de deteriorament en que es trobaven. La valoració social amb l'escala de Gijón podria ajudar a saber en quin punt del pronòstic es troba el pacient i fer recomanacions més adients en relació al seu estat de salut.

Dins els factors que contribueixen a l'autocura es troba el **suport social** [116,117], en aquest aspecte, tant l'estudi de cohorts com l'estudi qualitatiu posen de relleu la importància de les relacions socials en el dia a dia de les persones. Els pacients van valorar positivament la qualitat de les relacions i pocs pacients van reportar no tenir cercle social. Probablement, el nostre context social/familiar impliqui aquest suport entre persones. Es considera important contextualitzar les relacions socials ja que es coneix que per a altres poblacions el suport social no té la mateixa rellevància que al nostre context i per tant, aquests resultats no serien extrapolables a altres poblacions [118].

La manca de suport social en persones amb IC també afecta negativament al número d'hospitalitzacions [119]. Aquest fet pot estar relacionat amb l'ajuda que precisen les persones per mantenir una bona adherència al tractament farmacològic i no farmacològic. En aquest sentit, cal destacar que els pacients que formaven part de l'estudi de cohorts d'aquesta tesi, convivien principalment amb persones físicament dependents, les quals potser no podien oferir una atenció adequada als pacients i això contribuïa negativament a la mortalitat.

La valoració de les relacions socials és crucial no només en la IC i mortalitat. De manera general, es coneix que la solitud i l'aïllament social s'associen a una major incidència de malalties cardiovasculars i hospitalitzacions, fins i tot després de controlar els clàssics factors de risc cardiovasculars (alimentació, exercici i cessació tabàquica) [120].

Durant les entrevistes, els participants van destacar el paper dels cuidadors (formals o informals), per l'ajuda de les activitats de la vida diària i el suport emocional que poden proporcionar. En canvi, és conegut que els cuidadors poden sentir-se sobrepassats per la situació i experimentar ansietat, estrès o fatiga física i que aquesta situació influeix també negativament als pacients i al pronòstic de vida [121]. Per tant, la valoració social del pacient a l'atenció primària de salut, hauria d'acompanyar-se d'una valoració emocional i física del cuidador/a principal.

En aquest sentit, es considera necessari, continuar desenvolupant programes socials de recolzament a les persones amb IC per tal de millorar la salut mental, l'autoura i l'adherència al tractament.

En referència al **nivell socioeconòmic**, els primers estudis de Marmot et al [122] van establir una relació clara entre l'estatus econòmic i la mortalitat. Les mesures emprades per establir el nivell socioeconòmic van estar relacionades amb el tipus d'ocupació, els ingressos econòmics i el nivell d'estudis de les persones [123,124]. En canvi, en la cohort estudiada en aquesta tesi, no hi havia pràcticament diferències entre la mortalitat respecte els ingressos tot i tenir una gran proporció de pacients amb ingressos baixos (40,1%). És possible que el nostre sistema sanitari universal minimitzi l'efecte negatiu d'aquestes diferències econòmiques.

Per tal de representar diferents poblacions, l'estudi qualitatiu es va realitzar en diferents contextos i en persones amb diferent nivell d'estudis on existia variabilitat socioeconòmica [125]. En canvi, la experiència viscuda de les persones no va ser significativament diferent, i per tant, això també recolzaria el fet de que el nostre sistema social i sanitari, podria esmorteir algunes desigualtats.

El concepte "**locus de control**" es fa servir a psicologia per referir-se al nivell d'influència que l'individu creu que té sobre el curs de la malaltia. Un locus de control intern fa referència a la capacitat percebuda en modificar el curs de la malaltia amb les decisions personals, com per exemple, la dieta, o seguir les recomanacions sanitàries. En canvi, un locus de control extern, indica que la persona no creu tenir cap control sobre el curs de la malaltia [126].

Els pacients entrevistats consideraven que el curs de la malaltia era inevitable i tot i que algunes de les recomanacions (dieta i tractament farmacològic), eren practicables en el seu dia a dia, no sentien que tingués un impacte en les hospitalitzacions o en la seva qualitat de vida.

El fet que els pacients sentin que el tractament farmacològic no millora el seu pronòstic, pot ser un motiu pel qual podrien tenir una baixa adherència en cas que la presa del fàrmac dificulti alguna tasca en el dia a dia (p.e diürètics). En aquest sentit, els pacients busquen estratègies per tal que la seva vida diària sigui compatible amb la medicació (p.e supressió d'algun fàrmac puntualment o canvi de posologia) i aquestes no es perceben com una manca d'adherència sinó com una manera de mantenir una bona qualitat de vida [127].

Es considera rellevant una bona avaluació de l'adherència al tractament en els pacients amb IC. En aquest aspecte, es coneix que un recolzament telefònic per part d'experts, podria ajudar a millorar aquest locus de control [126] i per tant, de l'adherència al tractament, en canvi, la informació fins l'actualitat ha estat centrada en pacients amb IC i es desconeix l'impacte en la IC avançada.

A nivell simptomàtic, els pacients conviuen amb **dispnea/fatiga** crònica. D'acord amb els resultats obtinguts durant les entrevistes, estudis previs han trobat que la majoria dels pacients distingeixen la dispnea/fatiga en dues fases completament diferenciades: la que van sentir en el moment del diagnòstic (dispnea viscuda de manera abrupte), de la que senten en el seu dia a dia (dispnea crònica). L'impacte de la dispnea no es restringeix als símptomes físics i la discapacitat física que comporta, sinó que te un impacte emocional i els participants es senten espantats quan viuen aquest símptoma de manera més acusada en moments de descompensació cardíaca. A més, no tots els pacients distingeixen els períodes de descompensació, fet que els angoixa encara més [128,129].

A nivell **emocional**, les dones entrevistades expressaven sentiments de solitud, tristesa i inclús desesperació causada per les limitacions físiques que tenien degut a la malaltia. El constructe social sobre les dones en relació a ser cuidadores [130] no podia ser satisfet i probablement aquest fet empitjorava l'experiència.

En canvi, els homes entrevistats referien trobar-se relaxats i adaptats a la malaltia. Aquest fet pot estar relacionat amb la societat patriarcal actual on s'espera que els homes tinguin una aparença més "forta" i no expressin emocions [131]. Per tant, podrien mostrar-se millor adaptats a la malaltia.

No existeixen estudis previs que parlin sobre les diferències de gènere en persones amb IC avançada. Tot i que es coneix que la malaltia afecta de manera més primerenca als homes [132], la fragilitat afecta de manera més significativa a les dones [133] i aquestes, refereixen tenir una qualitat de vida inferior a la dels homes [134]. Es considera rellevant seguir investigant sobre les diferències de gènere en la IC avançada per tal que els professionals sanitaris puguin donar una millor resposta a les diferents necessitats dels homes i dones.

Durant les entrevistes en profunditat també es van explorar els **mecanismes d'adaptació** que les persones feien servir en el seu dia a dia, en aquest sentit, vam trobar que els pacients intentaven mantenir una actitud positiva. Els participants explicaven que gaudir de les "petites coses" de la vida i prendre el dia a dia amb més calma els ajudava a estar millor adaptats a la malaltia [135]. Aquests mecanismes d'adaptació, podrien millorar la qualitat de vida de les persones i millorar l'adherència al tractament [136,137].

Pel que fa a la **relació entre pacients-professionals de la salut**, les persones entrevistades referien generalment que el diagnòstic de la malaltia s'explicava durant una descompensació cardíaca en l'entorn hospitalari. Aquest context, no sempre garanteix la comunicació entre professional-pacient d'una manera fluida i relaxada i els pacients es poden sentir "sobrepassats", fet que afavoriria que no comprenguessin el diagnòstic.

Tot i que generalment els participants referien tenir bona relació amb els professionals sanitaris, sentien que el seguiment de la seva malaltia en períodes d'estabilitat no estava prou estandarditzat i les descompensacions es tractaven principalment a serveis d'urgències hospitalàries. A més, es coneix que els pacients perceben que la informació del pronòstic de la malaltia no és clara i reclamen una millor comunicació amb els professionals sanitaris [138]. Aquesta situació podria estar agreujada per una coordinació insuficient entre diferents nivells assistencials que faria que els professionals de l'atenció primària no disposessin de prou informació per al seguiment de la malaltia [139].

D'altra banda, les persones amb IC tenen necessitats canviants durant el curs de la malaltia i precisen una atenció centrada en la persona i ser valorades a nivell holístic i no només des de la vessant més física de la malaltia [138,140].

Per aquests motius, un dels models implementats en el nostre entorn amb l'objectiu de millorar aquest aspecte va ser el model de gestió de casos liderat per infermeres [86].

En aquesta tesi també es va investigar l' **efectivitat i la cost-efectivitat en l'entorn de l'atenció primària del model d'atenció de les infermeres GC.**

La revisió sistemàtica realitzada en aquesta tesi difereix de les anteriors ja que la població d'estudi tracta únicament a pacients amb IC avançada i les revisions fins l'actualitat havien estudiat la població d'IC en el seu conjunt (NYHA I-IV).
La revisió sistemàtica més recent va ser publicada l'any 2019 pel grup Cochrane de Takeda et al [93]. Tant aquesta revisió com d'altres realitzades sobre població amb IC [141,142], van trobar que la intervenció millorava la **mortalitat** global, en canvi la revisió publicada en aquesta tesi conclou que la intervenció no millorava la mortalitat per totes les causes. Probablement, degut a que els pacients es trobaven en l'estadiatge més avançat de la malaltia, el desenllaç va ser inevitable.

Tanmateix, és destacable el fet de que cap estudi inclòs a la revisió recollia l'efecte de la intervenció sobre la mortalitat per IC. Aquest fet, limita el coneixement sobre l'impacte en la mortalitat específica. Establir la causa de mort en els pacients amb IC és un procés complex, ja que, habitualment la IC té una causa subjacent (p.e cardiopatia isquèmica o malaltia arterial coronaria) i sovint, es fa servir aquesta afecció com a causa de la mort [37]. En aquest sentit, l'estudi de la mortalitat de la IC en pacients inclosos en gestió de casos és rellevant des del punt de vista de l'estudi de la mortalitat específica.

En relació a les hospitalitzacions per IC i per totes les causes, la revisió d'aquesta tesi conclou, que el programa de GC liderat per infermeres redueix les reaguditzacions que precisen d'hospitalitzacions de manera significativa. Els pacients amb IC avançada pateixen d'altres patologies concomitants, i és possible que el programa de GC no només estigui centrat en la IC, i que per tant, tingui un efecte global que impacti positivament a les hospitalitzacions per altres causes (p.e diabetis mellitus o malaltia pulmonar obstructiva crònica).
La literatura sobre aquest efecte és controvertida, l'estudi més actual realitzat en el nostre país publicat l'any 2022, conclou que la gestió de casos liderada per infermeres redueix les hospitalitzacions per totes les causes [143]. En canvi, la revisió del grup de Takeda et al [93], no va trobar canvis significatius en aquest aspecte. Probablement, la revisió de Takeda tot i ser la més complerta sobre la efectivitat del programa, no recull alguns dels estudis més recents, i per tant, podria ser que no estigui ajustada a la realitat actual sobre els efectes de la intervenció. En aquest sentit i degut a que existeixen estudis primaris posteriors avaluant el programa, es considera rellevant actualitzar la revisió sobre la efectivitat en la població IC en tots els seus estadiatges.

Igualment, en la revisió sistemàtica (RS) d'aquesta tesi s'observa que la intervenció va millorar la qualitat de vida de les persones dins el programa a mig termini (després dels 6 mesos del seguiment) i que aquesta millora es va mantenir fins als 12 mesos. Per tant, es necessita un període relativament llarg per trobar una millora i aquesta no és mantinguda en el temps. Segurament, és difícil millorar la qualitat de vida de manera duradora en les persones que pateixen una malaltia avançada. En canvi, el que sí que es va trobar va ser que la telemedicina no funcionava per millorar la qualitat de vida [144]. El fet de rebre visites presencials a domicili involucra el contacte humà, i segurament aquest té un efecte sobre la qualitat de vida. En aquest sentit, és possible que també tingui un efecte a nivell emocional, per tant, futurs estudis podrien avaluar l'efecte de les visites presencials en les emocions de les persones.

Tanmateix no es va observar una millora en l'autocura gràcies a la GC. Cal destacar que es van trobar només dos estudis que valoraven aquesta habilitat i els resultats van ser controvertits, probablement degut a que el temps de seguiment també ho era (el seguiment més curt mostrava millors valors d'autocura que els pacients que portaven més temps en seguiment per la gestora de casos). És possible pensar que, contràriament a l'efecte de la qualitat de vida, l'adherència a les recomanacions dels professionals és quelcom més aplicable a curt termini, i per a que aquest es mantingui en el temps, es precisa d'una motivació intrínseca important que fa que alguns pacients abandonin les pautes recomanades.

Es necessiten futurs estudis que cerquin com millorar l'adherència i com motivar als pacients amb IC avançada a seguir les recomanacions ja que s'ha demostrat que un bon nivell d'autocura pot reduir les reaguditzacions que precisen hospitalització [145].

Finalment es va recollir la cost-efectivitat de la intervenció. Aquesta tesi conclou que la gestió de casos liderada per infermeres podria ser rentable en alguns contextos amb un cost incremental per AVAQ des dels 14.027€ (costos del 2015) als 59.289€ (costos del 2009). Aquesta rendibilitat ve principalment marcada per la disminució dels costos relacionats amb els ingressos hospitalaris. Les intervencions no rentables podrien ser aquelles on el cost de la intervenció fos massa elevat. Altres estudis també han demostrat aquesta rendibilitat relacionada amb la disminució dels ingressos hospitalaris a la població d'IC en tots els seus estadiatges [146].

En els estudis inclosos en la revisió d'aquesta tesi, el preu del cost de la intervenció va ser molt variable i probablement depenia del número de professionals involucrat en el programa.

La millora dels AVAQ dels pacients amb IC en programes de GC ja s'havia publicat en estudis anteriors [147], en canvi, la novetat de la revisió publicada en el context d'aquesta tesi, radica en que el cost de la intervenció és major que en estudis en població d'IC general (3.746€/AVAQ pel grup de Takeda et al per a població IC general vs 14.027€/AVAQ per a població amb IC avançada).

Probablement, el fet de trobar-nos davant de pacients amb IC en fase avançada, requereixi intervencions més intensives i per tant, incrementi el cost per obtenir un AVAQ [93].

El model de gestió de casos liderat per infermeres podria ser un model cost-efectiu. Degut a que cap estudi inclòs en la revisió sistemàtica de la present tesi s'ha realitzat en el nostre entorn, es considera rellevant realitzar estudis sobre el perfil de cost-efectivitat de la GC liderada per infermeres al nostre país.

8.3 LIMITACIONS

Cal remarcar que els resultats obtinguts en els tres estudis publicats d'aquesta tesi s'apliquen a pacients amb insuficiència cardíaca avançada i no poden ser generalitzats a altres fases de la malaltia. Tanmateix, l'objectiu de la present tesi està centrat en aquest subgrup de pacients amb IC avançada.

L'estudi de cohorts retrospectiva va proporcionar una bona quantitat de dades relacionades amb les variables d'interès, però degut a que la base de dades utilitzada per l'anàlisi està creada amb finalitats clíniques i no de recerca, vam trobar limitacions en cercar totes les variables d'interès per a l'anàlisi. D'altra banda, l'anàlisi del risc social es va realitzar amb una escala validada al nostre entorn i per tant, alguns ítems com els *ingressos econòmics* haurien de ser adaptats a altres contextos. En canvi, pel que fa a la resta d'ítems, creiem que són universals i transferibles a altres països desenvolupats.

Durant la realització de l'estudi de cohorts i l'estudi qualitatiu, no vam poder recollir les variables del NT-proBNP ja que aquest paràmetre no era accessible dins l'entorn d'atenció primària de salut. Tanmateix, aquest paràmetre no s'utilitza per a la classificació de la severitat de la IC i pot ser que no sigui essencial en el maneig de la malaltia.

L'estudi qualitatiu va permetre una bona descripció en profunditat i interpretació de la vivència de la malaltia, d'altra banda i com a fet inherent a la metodologia emprada, els resultats no són extrapolables però si transferibles a altres contextos similars. A més, la població entrevistada patia d'altres malalties concomitants i per tant, cal tenir en compte aquest fet de cara a entendre l'experiència global de la persona.

La revisió sistemàtica aporta gran informació sobre l'efectivitat i cost-efectivitat de la intervenció en pacients amb IC avançada. D'altre banda, es va valorar el risc de biaix en 16 estudis dins la categoria "risc moderat" o "risc alt", i per tant, no foren inclosos al metaanàlisi, tot i així, van ser descrits de manera narrativa i van anar en la mateixa direcció que els resultats meta-analitzats.

Pel que fa a la intervenció de gestió de casos, cal valorar que les característiques d'aquesta poden diferir entre estudis i per mitigar això, es van descriure les particularitats de cada intervenció en una taula descriptiva.

Finalment els anàlisis de cost i cost-efectivitat s'han realitzat en països d'alta renda, per tant, es desconeix quina efectivitat té el programa en altres contextos.

8.4 FORTALESES

Els estudis publicats en aquesta tesi proporcionen nova informació sobre el pronòstic i vivència en el nostre context, mentre que la revisió sistemàtica proporciona una avaluació robusta sobre l' efectivitat i la cost-efectivitat del programa de GC en la població d'IC avançada.

Per analitzar l'estudi de cohorts, es va accedir a la base de dades més gran que pot proporcionar l'Atenció Primària (SIDIAP) en el nostre context i això va permetre obtenir una gran mostra de pacients.

La utilització d'una escala que combina diversos elements socials ofereix una visió integral sobre la valoració de l'impacte dels determinants socials.

D'altra banda, les entrevistes en profunditat van ser realitzades al domicili dels participants i per tant, es va aconseguir informació en el propi entorn del pacient. Aquest context pot facilitar l’exploració en profunditat de les vivències de les persones. A més, l’anàlisi de dades realitzada per un equip multidisciplinari s’emmarca en un model teòric que proporciona una informació estructurada. Els procediments de rigor emprats (triangulació de les dades, saturació de dades i la flexibilitat metodològica característica de la metodologia qualitativa) asseguren la validesa dels resultats.

La revisió sistemàtica resumeix l’efectivitat i la cost-efectivitat del programa de gestió de casos liderat per infermeres a la comunitat i per a la seva realització és va seguir la metodologia *Cochrane Collaboration*. El fet de realitzar la cerca en set bases de dades i no restringir el període de publicació, va proporcionar una visió àmplia dels estudis publicats. D’altra banda, el procés de selecció d’estudis i l’avaluació del risc de biaix per parells, va proporcionar rigor en els resultats meta-analitzats.

8.5 FUTURES LÍNIES DE RECERCA

Els resultats obtinguts en el marc d’aquesta tesi doctoral obren espai a noves preguntes d’investigació i línies de recerca:
Es necessiten futures investigacions que determinin de manera més precisa els mecanismes de l’entorn social que indiquen un pitjor pronòstic en els pacients amb IC avançada.

D’altra banda, sabem que l’adherència a les recomanacions específiques per a la IC pot millorar la qualitat de vida de les persones. En aquest sentit, hem trobat que la motivació per una bona autocura pot decréixer amb el pas del temps i seria precís que nous estudis investiguessin sobre l’impacte de diferents intervencions per a millorar-la.
Millorar el locus de control dels pacients i que sentin que poden millorar la seva qualitat de vida mitjançant les decisions que prenen en el seu dia a dia serà bàsic per adherir-se a les recomanacions dels professionals sanitaris.

A més, caldrà seguir investigant sobre les diferències de gènere. Durant la revisió sistemàtica presentada en aquesta tesi, no es va trobar representada la perspectiva de gènere en cap estudi primari. Les possibles diferències de gènere podrien afectar, inclús, a l’efectivitat dels programes de gestió de casos, i per tant, es necessiten nous assajos clínics amb perspectiva de gènere que tinguin en compte aquestes possibles diferències.

Pel que fa a l’avaluació de la intervenció de la gestió de casos liderada per infermeres, aquesta tesi obre alguns aspectes a analitzar en profunditat en nous assajos clínics:

En primer lloc, per tal d’avaluar la mortalitat especifica per IC, caldria reportar aquest resultat en les futures investigacions.

En segon lloc, vam trobar que les visites presencials tenien un efecte més beneficiós per a la qualitat de vida de les persones que la telemedicina. És possible pensar que les visites presencials també milloren la salut mental i proporcionen benestar emocional. En aquest sentit, futurs assajos clínics i estudis qualitatius sobre l’experiència d’estar en seguiment per un programa de gestió de casos, haurien de valorar aquest aspecte.

En tercer lloc, cal assenyalar que cap dels estudis primaris d’efectivitat i cost-efectivitat inclosos en aquesta revisió sistemàtica es va desenvolupar al nostre entorn. En aquest sentit i per facilitar la presa de decisions en salut, és necessari desenvolupar estudis de perfil de cost-efectivitat al nostre país.

Finalment, es van trobar una gran quantitat d’estudis primaris avaluant l’efectivitat de la GC sobre la població amb IC general que no es van poder incloure a la revisió degut a que la població analitzada es trobava en qualsevol de les fases de la malaltia. Degut a que probablement l’efecte de les intervencions sigui diferent en les diferents fases de la IC, es considera important realitzar un subanàlisi dels resultats del grup de població d’IC avançada.

9. CONCLUSIONS I IMPLICACIONS

9.1 CONCLUSIONS

- Els pacients amb IC avançada amb problemàtica social, tenen taxes de mortalitat més altes que els pacients amb millor suport social, independentment de la seva comorbiditat i estat funcional. Tenir en compte els determinants socials de salut en el seguiment dels pacients, permetria als professionals sanitaris oferir suport necessari reduint la vulnerabilitat en la fase més avançada de la malaltia.

- El suport social és un element clau del punt de vista de la mortalitat i des de l'experiència de vida dels pacients amb IC avançada.

- Pel que fa a l'impacte de la IC avançada, es va trobar que el locus de control era percebut com a extern ja que els participants sentien que no eren capaços d'influenciar en el curs de la malaltia.

- Existeixen diferències de gènere en la representació emocional. Les dones refereixen més símptomes depressius i els homes es mostren calmats i inclús amb esperança de ser curats. En aquest aspecte, els professionals sanitaris haurien d'adaptar les seves intervencions de suport emocional basant-se en la perspectiva de gènere.

- Els pacients amb IC avançada pensen que algunes de les recomanacions que donen els professionals són, generalment, fàcils de seguir, en canvi, algunes altres no les poden realitzar degut a la limitació física amb la que viuen. Per tant, els professionals sanitaris haurien de tenir en compte l'estat físic dels malalts i adaptar les recomanacions a la dependència de les persones.

- Els pacients senten que la comunicació amb els professionals sanitaris és insuficient, i per tant, noves estratègies d'atenció haurien de desenvolupar-se amb la finalitat de millorar la relació professional-pacient.

- La gestió de casos liderada per infermeres redueix els ingressos hospitalaris per totes les causes i per IC, i a més millora la qualitat de vida a mig termini en els pacients que estan dins el programa. Tot i que no va ser un resultat estadísticament significatiu, la supervivència i l'autocura també podrien millorar amb la intervenció.

- Els costos de la implementació d'un programa de gestió de casos tenen un rang molt ampli segons els professionals implicats i el context i van des de 4,975$ a 27,538€. El model de gestió de casos liderat per infermeres podria ser un model cost-efectiu.

9.2 IMPLICACIONS I RECOMANACIONS PER A LA SALUT PÚBLICA

Els estudis que s’han presentat en aquesta tesi, aporten nou coneixement sobre els determinants pronòstics de mortalitat, vivència de la IC avançada, cost i cost-efectivitat del programa de gestió de casos liderat per infermeres a l’atenció primària.

Degut a que s’ha demostrat la gran rellevància del suport social en els pacients amb IC avançada tant en la supervivència com en la vivència de la malaltia, és recomanable que les polítiques socials i de salut considerin aquest fet i desenvolupin programes socials per a aquests pacients. El suport social operatiu és de gran utilitat per poder completar les activitats de la vida diària, a més existeix un efecte més enllà de la operativitat, ja que els pacients valoren el contacte amb les persones i això fa probablement que millori la seva salut mental.

D’altra banda, en aquesta tesi s’ha demostrat que el risc social mesurat amb un instrument disponible a l’entorn de atenció primària, podria predir la mortalitat dels pacients, i per tant, es considera rellevant incloure la valoració d’aquest risc mitjançant l’escala sòcio-familiar de Gijón a tots els pacients amb IC avançada. Conèixer l’entorn i el suport del pacient amb l’escala mencionada ajudaria a determinar quins pacients estan a més risc de mortalitat i per tant, contribuiria a ajustar les recomanacions que els professionals donen als pacients i inclús a prendre altres decisions relacionades amb el final de vida.

Per últim, en aquesta tesi s’ha descrit que els pacients perceben fragmentació entre diferents nivells assistencials i en ocasions descoordinació de l’atenció. Això posa de relleu la importància de la figura de la gestora de casos en pacients on existeix complexitat com és el cas de la IC avançada. El model de gestió de casos liderat per infermeres ha demostrat resultats en salut i podria ser un model cost-efectiu. Degut a que cap estudi inclòs en la revisió sistemàtica de la present tesi s’ha realitzat al nostre entorn, es considera rellevant realitzar estudis sobre el perfil de cost-efectivitat de la GC liderada per infermeres al nostre país per tal de facilitar la presa de decisions en salut.

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11. ANNEXES

11.1 CONSENTIMENT INFORMAT DE L’ESTUDI “VIVÈNCIES DELS PACIENTS AMB INSUFICIÈNCIA CARDÍACA AVANÇADA”

(Versió Català)

Títol de l’estudi: Vivències dels pacients amb insuficiència cardíaca avançada.

Introducció

Em dirigeixo a vostè per informar-lo sobre un estudi de recerca al qual se'l convida a participar. La intenció d'aquest document és que rebeu la informació correcta i suficient perquè pugueu decidir si voleu o no participar-hi. Per això és important que el llegeixi i pugui aclarir els dubtes que puguin sorgir.

La seva participació en aquest estudi és voluntària i pot retirar el consentiment en qualsevol moment sense que això alteri la relació amb el personal sanitari ni amb les cures que rep.

Per què és important aquest estudi?

L’objectiu principal de l’estudi és conèixer com viuen les persones que pateixen insuficiència cardíaca avançada. Conèixer la vostra experiència ens pot ajudar a millorar les cures que s'ofereixen a les persones que pateixen insuficiència cardíaca. Perquè vostè ens pugui explicar la seva experiència, us farem una entrevista.

Vostè pot negar-se en qualsevol moment a respondre alguna de les preguntes que se li faci. L'entrevista es realitzarà al seu domicili, per facilitar-ne la realització i tindran una durada d'entre 60 i 90 minuts. Al lloc de l'entrevista només es trobarà vostè i l'entrevistadora, i es registrarà l'entrevista amb una gravadora d'àudio. Aquests enregistraments només els escoltarà l'equip investigador per transcriure'ls i analitzar-los posteriorment. En cap moment s'escriurà el seu nom a la transcripció, sinó que s'utilitzarà un altre nom que vostè mateix triarà. Hi ha la possibilitat de contactar amb vostè telefònicament més tard per preguntar-li si està d'acord amb allò que l'equip de recerca ha analitzat de la seva entrevista.

Aquest estudi no us produirà cap risc per a la vostra salut. No se us realitzaran proves complementàries ni visites mèdiques extres. Es calcula que hi participaran un total de 14 persones.

Beneficis derivats de la seva participació a l'estudi

S'espera que els resultats adquirits gràcies a la seva participació ajudin altres persones que com vostè, pateixen insuficiència cardíaca.

Confidencialitat

El tracte, la comunicació i la cessió de les dades és de caràcter personal de totes les persones que participin a l'estudi. Les dades recollides només les poden veure l'equip investigador. Les entrevistes s'identificaran amb un pseudònim de manera que el vostre nom no s'escriurà en cap moment. Per tant, la identitat no serà revelada en cap moment.

Altra informació rellevant

Si voleu retirar el vostre consentiment per participar en aquest estudi, podeu exigir la destrucció del material d'àudio de l'entrevista. En signar el consentiment que se us adjunta a continuació, es compromet a complir els procediments de l'estudi que s'han exposat.

Aquest estudi es fa sota la supervisió de la Unitat de Recerca en Atenció Primària de Barcelona, i de l'Institut de Recerca IDIAP-Jordi Gol.

Si teniu algun dubte o desitgeu més informació no dubteu a contactar amb la investigadora principal d'aquest estudi: Caterina Checa Jiménez (Tel. 902 500 179); ccheca@eapdretaeixample.cat

Consentiment informat

Títol de l’estudi: Vivències dels pacients amb insuficiència cardíaca avançada.

Jo (nom i cognoms)____

He llegit el full d'informació sobre l'estudi i he pogut fer les preguntes. He rebut prou informació d'aquest estudi i he parlat amb la investigadora:_____________________________(nom i cognoms).

Entenc que la meva participació és voluntària i que em puc retirar de l'estudi:

- Quan ho desitgi
- Sense donar explicacions
- Sense que això repercuteixi en les cures que estic rebent

Dono lliurement el meu consentiment per participar en aquest estudi:

Signatura del pacient	Signatura de la investigadora
Data	Data

(Versió Castellà)

Título del estudio: Vivencias de los pacientes con insuficiencia cardíaca avanzada.

Introducción

Me dirijo a usted para informarle sobre un estudio de investigación al que se le invita a participar. La intención de este documento es que reciba la información correcta y suficiente para que pueda decidir si quiere o no participar en el mismo. Por eso, es importante que lo lea y pueda aclarar las dudas que puedan surgir.

Su participación en este estudio es voluntaria y puede retirar el consentimiento en cualquier momento sin que esto altere la relación con el personal sanitario ni con los cuidados que recibe.

¿Por qué es importante este estudio?

El objetivo principal del estudio es conocer cómo viven las personas que padecen insuficiencia cardíaca avanzada. Conocer su experiencia nos puede ayudar a mejorar los cuidados que se ofrecen a las personas que padecen insuficiencia cardíaca. Para que usted nos pueda explicar su experiencia, le realizaremos una entrevista.

Usted puede negarse en cualquier momento a responder alguna de las preguntas que se le realice. La entrevista se realizará en su domicilio, para facilitar su realización y tendrán una duración de entre 60 y 90 minutos. En el lugar de la entrevista solamente se encontrará usted y la entrevistadora, y se registrará la entrevista con una grabadora de audio. Estas grabaciones sólo las escuchará el equipo investigador para transcribirlas y analizarlas posteriormente. En ningún momento se escribirá su nombre en la transcripción, sino que se utilizará otro nombre que usted mismo escogerá. Cabe la posibilidad de contactar con usted telefónicamente más tarde para preguntarle si está de acuerdo con lo que el equipo de investigación ha analizado de su entrevista.

Este estudio no le producirá ningún riesgo para su salud. No se le realizarán pruebas complementarias ni visitas médicas extras. Se calcula que participaran en este estudio un total de 14 personas.

Beneficios derivados de su participación en el estudio

Se espera que los resultados adquiridos gracias a su participación ayuden a otras personas que como usted, padecen insuficiencia cardíaca.

Confidencialidad

El trato, la comunicación y la cesión de los datos es de carácter personal de todas las personas que participen en el estudio. Los datos recogidos solo los puede ver el equipo investigador. Las entrevistas se identificarán con un pseudónimo de manera que su nombre no se escribirá en ningún momento. Por tanto, su identidad no será revelada en ningún momento.

Otra información relevante

Si usted desea retirar su consentimiento para participar en este estudio, puede exigir la destrucción del material de audio de la entrevista. Al firmar el consentimiento que se le adjunta a continuación, se compromete a cumplir con los procedimientos del estudio que se han expuesto.

Este estudio se realiza bajo la supervisión de la Unidad de Investigación en Atención Primaria de Barcelona i del Instituto de Investigación IDIAP-Jordi Gol.

Si tiene alguna duda o desea más información no dude en contactar con la investigadora principal de este estudio: Caterina Checa Jiménez (Tel. 902 500 179); ccheca@eapdretaeixample.cat

Consentimiento informado

Título del estudio: Vivencias de los pacientes con insuficiencia cardíaca avanzada.

Yo (nombre y apellidos)____

He leído la hoja de información sobre el estudio y he podido hacer las preguntas sobre el mismo. He recibido información suficiente de este estudio y he hablado con la investigadora:______________________________(nombre y apellidos).

Entiendo que mi participación es voluntaria y que puedo retirarme del estudio:

- Cuando lo desee
- Sin dar explicaciones
- Sin que esto repercuta en los cuidados que estoy recibiendo

Doy libremente mi consentimiento para participar en este estudio:

Firma del paciente	Firma de la investigadora
Fecha	Fecha