UNIVERSITY of STIRLING

In conjunction with

Edinburgh Napier UNIVERSITY

Evidence of the Effectiveness and Patient Experience of Formalised Social Support for People with a Diagnosis of Heart Failure

Final Report to Chest, Heart & Stroke Scotland (June 2015)

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Appendix 1 Data Extraction of included studies

Key:

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1.1 Introduction

This systematic review was undertaken during December 2014 to June 2015, and was commissioned by Chest, Heart and Stroke Scotland (CHSS). The review team comprised of systematic review experts, and experts in heart failure and/or loneliness.

1.2 Aim and Objectives

1.2.1 Aim: To assess, grade and synthesize evidence of the effectiveness and patient experience of formalized social support for people with a diagnosis of heart failure

1.2.2 Objectives:

1. To identify and deepen the knowledge and understanding of the patient experience of formalized social interventions and its impact on the quality of life on people with a diagnosis of heart failure.

2. What are the causes of loneliness among people with a diagnosis of heart failure?

3. What are the needs of patients with heart failure who experience loneliness?

4. What is the impact of social interventions on health and functional outcomes?

5. How do social interventions influence knowledge of the condition and engagement with self-care?

6. Identify the use of validated measures that evaluate the effect of social interventions.

1.2.3 Definitions

Formalised Social Interventions: any support offered by voluntary or other agencies (e.g. befriending, either one-to-one or group based) and/or peers (e.g. lunch clubs, social networking sites) to service users and/or carers. Educational interventions were included where there was also an identified element of social support within it (educational interventions only were excluded).

1.2.4 Participants: Age over 40 years; Diagnosis of heart failure (where multiple co-morbidities, data can be extracted for heart failure)

1.2.5 Inclusion criteria

- Written in English language
- Over last 10 years
- Quantitative studies including randomized control trials, experimental and other studies were quantitative analysis is undertaken
- Qualitative studies
- Reviews with meta-analysis
- Must have evaluative outcome(s) measured and/or explored

1.2.6 Exclusion criteria

- Text/opinion papers
- Non-English language
- Papers published more than 10 years ago

1.2.7 Outcomes

Primary: Loneliness and other measures of social isolation

Secondary: Social isolation; Social support; Health outcomes; Admission rates to hospital; Anxiety and depression scales; Compliance/adherence with medication and other health interventions/advice; Mortality rates; Satisfaction rates; Patient experience questionnaire and exploration.

2.1 Search Strategy

Systematic searches were conducted across relevant health databases. For primary research the topic based databases Dynamed and UpToDate were used along with the NICE and SIGN guidelines sites. For the secondary literature the following databases were searched: Campbell and Cochrane Library, Cumulative Index of Nursing and Allied Health Literature (CINAHL), PsycINFO, MEDLINE, EmBase, ASSIA, Social Care Online, Web of Knowledge and SCOPUS. Published articles in peer-reviewed journals from database inception were included (detailed below). Reference lists and published reviews/meta-analyses will also be searched. All titles and abstracts have been screened and relevant full-text versions retrieved by two reviewers.

Example search using subject headings/keywords: Strategy used in Ovid MEDLINE®

Database: Ovid MEDLINE(R) 1946 to Present with Daily Update

Search Strategy:

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1 exp heart failure/ (91767)

2 exp myocardial infarction/ (152587)

3 (heart failure or myocardial infarction or heart attack*).af. (313491)

4 1 or 2 or 3 (318378)

5 exp social support/ (54416)

6 (formal* social support* or social support*).af. (62948)

7 (charity or charities or volunt* agenc* or volunt* organ* or volunt* sector* or third sector* or 3rd sector* or social network* or peer* support* or support* peer* or peer* network* or network* peer* or befriend* or be-friend* or lunch*).af. (26245)

8 5 or 6 or 7 (83870)

9 exp Attitude to Health/ or exp Attitude/ or exp Attitude to Death/ (437966)

10 exp patients/ (71318)

11 (patient* or individual* or servic* user* or user* or servic*).af. (6165042)

12 (experienc* or feel* or thought* or opinion* or attitud* or involv* or knowledg*).af. (2989369)

13 (need* or want* or requir* or desir* or necessit*).af. (2451204)

14 or/9-13 (8878811)

15 exp social isolation/ (14477)

16 exp loneliness/ (2329)

17 (lonel* or isolat* or detach* or remot* or rural*).af. (1772730)

18 (caus* or reason or reasons or sourc* or effect* or impact*).af. (6480532)

19 exp quality of life/ (126204)

20 exp Treatment Outcome/ or exp Patient Outcome Assessment/ or exp "Outcome Assessment (Health Care)"/ or exp "Outcome and Process Assessment (Health Care)"/ (771270)

21 exp patient admission/ (19344)

22 exp patient readmission/ (8924)

23 exp patient satisfaction/ (65803)

24 exp consumer satisfaction/ (83577)

25 exp "Patient Acceptance of Health Care"/ (177614)

26 exp Compliance/ or exp Patient Compliance/ (61853)

27 exp Medication Adherence/ (8890)

28 exp self-care/ (43187)

29 exp Anxiety/ or exp Anxiety Disorders/ (126058)

30 exp depression/ (82267)

31 exp depressive disorder/ (85433)

32 or/15-31 (8350957)

33 exp case reports/ or exp clinical conference/ or exp clinical trial/ or exp comparative study/ or exp consensus development conference/ or exp evaluation studies/ or exp in vitro/ or exp meta-analysis/ or exp multicenter study/ or exp "scientific integrity review"/ or exp twin study/ or exp validation studies/ (4652129)

34 evaluat*.af. (2478328)

35 evaluat*.af. (2478328)

36 quantitativ*.af. (459452)

37 exp Randomized Controlled Trials as Topic/ or exp Clinical Trials as Topic/ or exp Random Allocation/ or exp Double-Blind Method/ (468371)

38 (Randomi?ed Control* Trial* or Randomi?ed Control* stud*).af. (519008)

39 exp meta-analysis/ (54725)

40 (metaanal* or meta-anal*).af. (86382)

41 exp "Review Literature as Topic"/ (8137)

42 (systematic* review* or review* systematic*).af. (64843)

43 exp qualitative research/ (22427)

44 quantitativ*.af. (459452)

45 evaluation studies as topic/ or exp clinical trials as topic/ or exp validation studies as topic/ (415713)

46 or/33-45 (6812362)

47 4 and 8 and 32 and 46 (341)

48 limit 47 to (english language and yr="2003 - 2015") (232)

49 health social network*" OR "online support group*" OR "social network support group*" OR "virtual communit*" OR "online patient social network*" OR "on-line patient social network*") AND ("heart failure" OR "cardiac failure

Example search using keywords: Strategy used in Web of Knowledge

(TOPIC: ("heart failure" OR "myocardial infarction*" OR "heart attack*") AND **TOPIC:** ("social support*" OR charity OR charities OR "volunt* agenc*" OR "volunt* organ*" OR "volunt* sector*" OR "third sector*" OR "3rd sector*" OR "social network*" OR "peer support*" OR "support* peer*" OR "peer network*" OR "network* peer*" OR befriend* OR "be-friend*" OR lunch*) AND **TOPIC:** (lonel* or isolat* or detach* or remot* or rural*) AND **TOPIC:** ("clinical trial*" or "case report*" or "comparative stud*" or "evaluat* stud*" or metaanal* or "meta-anal*" or multicentr* or multicenter* or "multi-centr*" or "multi-center*" or "twin stud*" or "validation stud*" or random* or "systematic* review*" or qualitativ* or quantitativ*) AND (Timespan=2000-2014 AND Search language=English).

2.2 Screening and data extraction

We will report the screening and selection process and data extraction and synthesis, within this section, using the PRISMA statement recommendations.

MR independently screened all titles and abstracts (n=1016) identified from searches to determine which met the inclusion criteria. LA conducted a random sample selection of 10% of the papers MR included and excluded. Where there was disagreement MR and LA met and agreement was reached on whether to include or exclude. A total of 50 papers have been included for the next phase. All 50 full text papers identified as potentially relevant have been retrieved by MR and RP.

Two reviewers (WL, SW) independently screened full text articles for inclusion or exclusion, with discrepancies resolved by discussion. JD conducted a 10% random sample of both reviewers data extraction to ensure consistency in data extraction. All potentially relevant papers excluded from the review at this stage were listed as excluded studies (n=41), with reasons provided (Table 1).

Table 1: Excluded Studies and rationale for exclusion

Author(s)	Rationale for exclusion
Bernard et al. (2012)	• Formalised social support interventions were not defined as the intervention
Cash-Gibson et al. (2012)	• Cochrane Review Protocol – no completed review data available
Chiaranai C, Salyer J, and Best A.(2009)	• The effect of social support on participants' self-care was not measured.
Chung et al.	• Formalised social support interventions were not defined as the intervention
De Smedt R, Jaarsma T, Ranchor A, van der Meer K, Groenier K, Haaijer-Ruskamp F, and Denig, P (2012)	• While this study found that those who experience adverse drug events seek social support and information as a coping strategy, it is not known what effect / influence these things have on their knowledge of medicines for heart failure or their self-management of this condition. This study therefore, does not provide any data that could help to answer the objectives of the systematic review.
Demers C, Patterson C, Archer N, Coallier J, Strachan P, Keshavjee K, Thabane L, Spencer F, Cockhill C, Foster G, Gwadry-Shridar F (2014)	• No formalised social intervention.
DeWalt DA, Pignone M, Malone R, Rawls C, Kosnar MC ,George G, Bryant B, Rothman RL, Angel B (2004)	• No formalised social intervention.
Dumaij A, and Tijssen E (2011)	• Very small proportion of heart failure patients in the sample. Results from patients with different diagnoses were not reported separately and so difficult to draw conclusions for heart failure patients.
Elloumi et al. (2012)	• Development of research measures, not research data
Fahlberg (2011)	• Formalised social support interventions were not defined as the intervention
Gott M, Barnes S, Payne S, Barker C, Seamark D, Garballa, S (2007)	• This paper fails to address any of the objectives in the systematic review
Guez-Artalejo FR, Guallar-Castillo P, Herrera MC, Otero CM, Chiva MO, Concepcio C, Carren N , Ochao O,Banagras JR, Pascual , CRG (2006)	• No formalised social intervention.
Haley et al. (2011)	• Formalised social support interventions were

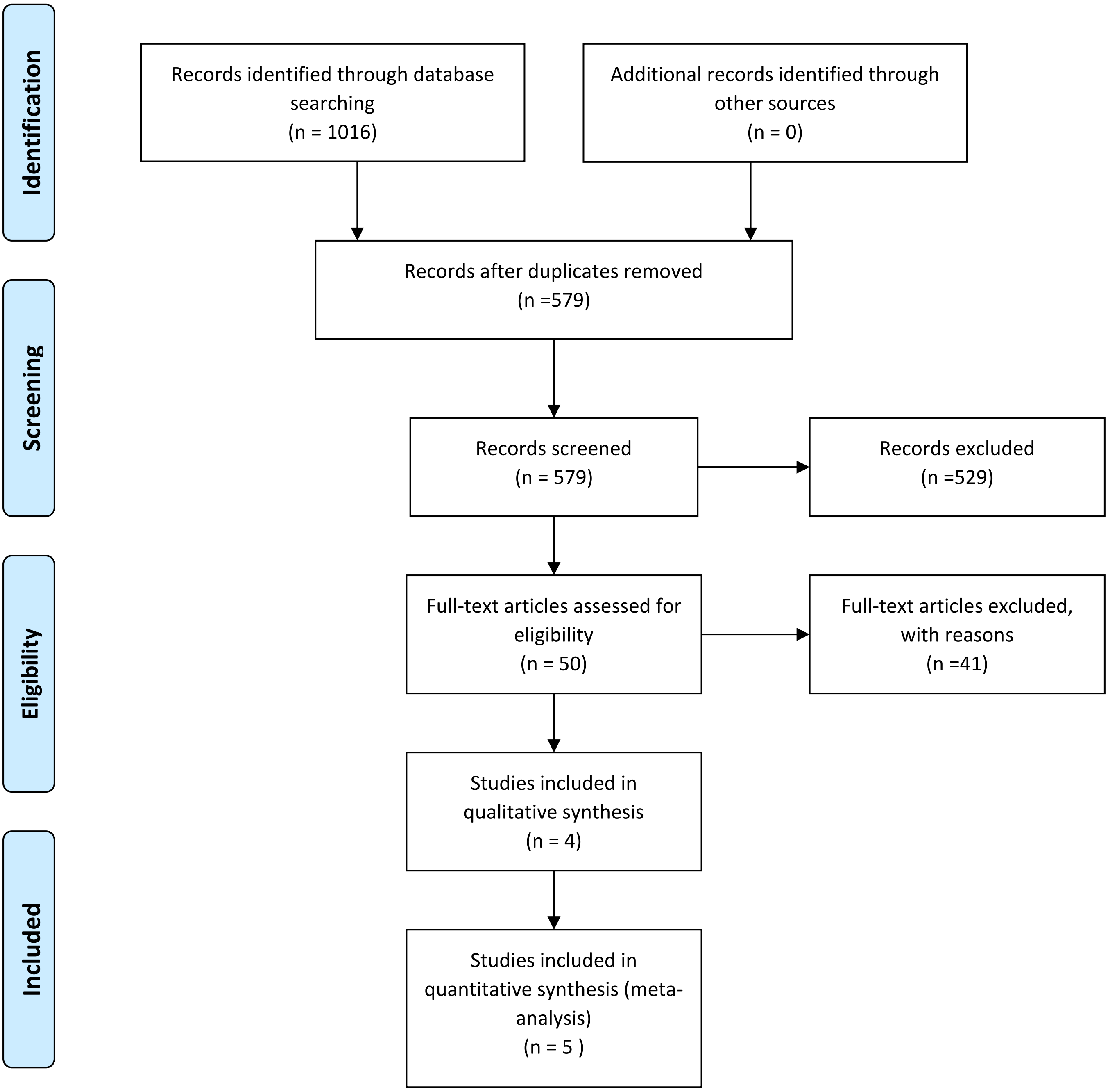
	not defined as the intervention
Hammer (2005)	- Interventions were carried out by nurses
Hawthorne G. (2006)	- There was no mention that the sample contained any heart failure patients and so this should not be included in the systematic review.
Heo S, Moser D, Chung M, and Lennie T.(2012)	- The findings from this study do not address any of the objectives of the systematic review
Hong L, Morrow-Howell N, Proctor E (2006)	- This paper fails to address any of the objectives in the systematic review
Horne G, and Payne S (2004)	- The discussion section of the document surmises that those who were housebound as a result of their heart failure were lonely but this was not particularly evident in the findings reported. This suggests some reporting bias. The findings of this study have little to contribute to the objectives of the systematic review.
Howie-Esquivel et al. (2014)	- Intervention was defined as a health profession intervention programme with no social support defined
Huang T, Moser D, Hsieh Y, Gau B, Chiang F, and Hwang S.(2013)	- This paper fails to address any of the objectives in the systematic review.
Hughes HA and Granger BB (2014)	- No formalised social intervention.
Inglis SC, Clark RA, Finlay A, McAlister FA, Ball J, Lewinter C, Cullington D, Stewart,S, Cleland J (2008)	- No formalised social intervention.
Isaksen A, and Gjengedal E.(2006)	- There are no reports of any of the patients in the study having heart failure
Lofvenmark et al. (2009)	- Formalised social support interventions were not defined as the intervention
Luttik M, Jaarsma T, Moser D, Sanderman R, and van Veldhuisen D (2005)	- This publication focuses more on social support rather than social interventions and so does not fit with the objectives set for the systematic review.
McLaughlin TJ, Aupont O, Bambauer KZ, Stone P, Mullan MG, Colagiovanni J, Polishuk E, Johnstone M, Locke SE (2005)	- This paper fails to address any of the objectives in the systematic review
McLaughlin MA (2010)	- Opinion piece. This paper fails to address any of the objectives in the systematic review
Menzies de Leon et al. (2009)	- Intervention was defined as a health profession training programme with no social

	support defined
Murberg (2004)	- Formalised social support interventions were not defined as the intervention
Nasstrom L, Jaarsma T, Idvall E, Stromberg A (2013)	- This paper fails to address any of the objectives in the systematic review
Neto et al. (2014)	- Primary outcome not included as an outcome measure within this study
Paget T (2010)	- No formalised social intervention. This paper fails to address any of the objectives in the systematic review
Rocca P, Nerr P, Locatelli B, Villa MT, Pisori M, Tespilli M, Giudici V (2013)	- This paper fails to address any of the objectives in the systematic review
Samartzis L, Dimopoulos S, Tziongourou M, Nanas S (2013)	- This paper fails to address any of the objectives in the systematic review
Sane, RM (2012)	- This paper fails to address any of the objectives in the systematic review
Stamp (2014)	- Formalised social support interventions were not defined as the intervention
Strachan et al. (2014)	- Formalised social support interventions were not defined as the intervention
Tsai (2008)	- Thesis not available online
Winningham and Pike (2007)	- Population was older adults and not people with diagnosis of heart failure
Winningham R, and Pike N (2007)	- This study has no mention of including heart failure patients and so it does not meet the criteria for inclusion.
Yu DSF, Lee DTF, Kwong ANT, Thompson D, Woo J (2007)	- This paper fails to address any of the objectives in the systematic review

Data were extracted using a Data Extraction Tool (Appendix I) of included studies (n=9) by SW and WL, and collated into a findings and data synthesis section by JD.

Figure 1 summarises the identification, screening, eligibility and data extraction from the studies included within this review.

PRISMA 2009 Flow Diagram: Figure 1



3.1 Findings

There were nine included studies which comprised of four Randomised Control Trials (RCTs), one quantitative study, one mixed method study and two qualitative studies and one literature review. Appendix I contains the data that were extracted from each included study using the data extraction sheet.

3.1.1 RCT and quantitative studies: overview of methodological quality

The RCTs were assessed for risk of bias, and this is summarised in Table 2 below:

Table 2: Risk of bias in RCT studies

	Random sequence generation (selection bias)	Allocation concealment (selection bias)	Blinding of participants and personnel (performance bias)	Blinding of outcome assessment (detection bias) (patient reported ouctomes)	Blinding of outcome assessment (detection bias)	Incomplete outcome data (attrition bias) (short-term 2-6 weeks)	Incomplete outcome data (attrition bias) (long-term >6 weeks)	Selective reporting (reporting bias)
Bakan & Akyol (2007)	🔴	🔴	🔴	🔴	🔴	🟢	🟢	🔴
Dickson et al. (2014)	🟢	🔴	🔴	🔴	🟢	🔴	🔴	🟢
Heisler et al. (2013)	🟢	🟢	🔴	🔴	🟢	🔴	🔴	🟢
Yu et al. (2009)	🟢	🔴	🔴	🔴	🟢	🟢	🟢	🟢

🟢	Low risk of bias
🔴	High risk of bias

The four RCT studies were identified as having risk of bias particularly in the following areas:

- Blinding of participants was not possible due to the nature of the intervention(s) in 100% of studies
- Detection bias was minimised in three out of four studies for outcome assessments (which were not patient reported outcomes)
- All patient reported outcomes were at risk of detection bias in all of the studies
- Attrition bias was at high risk in 50% of the studies
- Random sequence generation was explained in 75% of the studies, while only one was able to minimise allocation concealment.

Therefore none of the studies were able to minimise all sources of risk, with the best being Yu et al. (2009) and the worst being Bakan and Akyol (2007).

Synthesis of the data from RCTs was not appropriate due to the divergence of interventions, and outcome measures used within the four RCT studies.

The one quantitative study (Hart-Wright et al. 2006) that was included did not detail the research methodology used and therefore risk of bias (e.g. selection bias, attrition bias, reporting bias) cannot be assessed. Therefore the ability to replicate this study would be questionable, as would be representativeness of the findings.

3.1.2. Mixed method and qualitative studies: overview of methodological quality

The mixed methods study by Heisler et al. (2007) had a number of limitations: it had a relatively small sample (n=20) and was described as an assessment of feasibility and acceptability. The study used a pre-post design and it is not possible to conclude that this intervention (or which part of the intervention) affected depressive symptoms. The authors also suggest that a pre-intervention measure of social support may be advantageous to future studies of this kind.

The qualitative Grounded Theory study by Lockhart et al. (2014) reported some limitations: participants (n=18) who were engaged with the interventions were much more likely to engage in the research interviews than those participants who did not engage within the intervention (n=10, due to difficulty in recruitment of this group), and this may have skewed the research data presented in favour of the high users of the intervention. The author state that theoretical saturation was reached within the engaged participants while not in the non-engaged participants. More interviews may have revealed additional themes, but the researchers' state that each theme reported was expressed by multiple non-engaged participants. The researchers suggest that matching of pairs within the peer support program in different way may affect the content of the interviews. There is no reporting of member validation of the emerging themes.

In the qualitative study by LaFramboise et al. (2009), the sample size was small (n=13), making results difficult to generalise to the wider HF population. There was a time lapse, varying between six months to two years, since the use of the intervention that was being considered. Therefore the study could be biased since it was relying on participants' recall of their experience of using the tele health device. Reporting of member validation was positive. However, as with Lockhart et al.'s study (2014), the research team were only able to recruit one participant who had used the Health Buddy for a minimum of 30 days, while the other participants (n=12) had used it for the entire 6 months: therefore the data presented could be skewed towards high users of Health Buddy (LaFramboise et al. 2009).

In the literature review by Medina et al (2013), there was an overview provided of the search terms used but the inclusion/exclusion criteria for selection of studies was not included. There was no evidence of independent data screening or extraction, nor was there a systematic approach to data extraction. However, this was the only paper found on online support groups, and although the search could be subject to bias, it was included within this review.

3.2 Synthesis of findings

Therefore a narrative overview of these RCTs and other studies included within the review will be presented using a thematic scheme.

From the findings extracted from the studies, there were 4 key themes identified:

- Impact on self-care: knowledge and abilities
- Types of formalised social interventions within the literature

- Patient needs and experience
- Impact on health and/or social outcomes

Impact on self-care

Knowledge

One aspect of self-care is the issue of the knowledge: Participants acknowledged the use of the tele health intervention, Health Buddy, as teaching them about HF in a way that promoted self-management and comprehension about their condition (LeFramboise et al. 2009).

In the literature review by Medina et al. (2013), one study cited suggested that participants' postings online demonstrated a search for information where the patient felt comfortable asking difficult questions, and acquiring knowledge from others. While another study demonstrated that a moderated group had a greater influence on online support than an unmoderated group.

Abilities

In a study using a tele health device, Health Buddy, LeFramboise et al. (2009) produced themes that were generally positive such as 'technologically easy' and 'convenient'. The Health Buddy also provided "smaller pieces of information over time", providing reinforcement of education, important reminders about the daily management of HF, daily questions about self-management and ultimately participants reported that they were motivated to monitor and manage their HF symptoms.

The removal of Health Buddy at the end of the intervention revealed that there was inconsistent self-management after the intervention was removed: therefore this suggests that post-intervention management should be considered in future studies (LeFramboise et al. 2009).

Types of formalised social interventions within the literature

Dickson et al. (2014) discuss the use of delivering a community-based skill building intervention using lay health educators. This was viewed by the authors as providing an alternative to clinic or home-based teaching.

The essential elements of the self-care skill building intervention are based on the authors prior work that adequate self-care requires skill in the daily behaviours related to self-care maintenance (e.g. Adherence to a low salt diet, complex medication regimens, symptom monitoring) and skill in making decisions about signs and symptoms (e.g. diuretic titration)

This theoretically-based intervention was designed to be delivered in a group setting by a lay health educator. This model leveraged the unique role of health educators who have a degree and qualification relating to health education, to promote skill-building in self-care using a well-defined protocol, provide reinforcement of the clinical plan of care and additional lifestyle coaching related to HF self-care, and facilitate problem solving including access to care.

The skill building self-care intervention began with an assessment of each individual's current knowledge of HF, level of tactical skill (e.g. low salt meal preparation), and any specific situations (e.g. cultural and social norms) that needed to be considered in building these skills. Skill-building exercises focused on firstly, skill deficits (e.g. how to read food labels) and, secondly, managing common as well as unique situations (e.g. ordering food when eating out, managing diuretics while traveling) through practice and role-playing exercises.

The intervention was delivered in a group setting of 4–8 participants and held in a community senior centre. Twice weekly 60 min sessions were provided over the course of 4weeks.

Findings in this study demonstrated that the intervention improved the essential behaviours of self-care maintenance and management as well as HF knowledge. Similarly, the result of improved self-care at 1-month suggests the effectiveness of the group environment that allowed for ongoing support and dialogue with experts and peers. Therefore, the authors suggest that the significantly better self-care results at 3-months in the intervention group reflect the potential for sustainability of the intervention, but acknowledge a longer follow up period is necessary to capture the lasting effects.

The intervention conducted by Lochart et al. (2014) focused on the use of peer support. A successful diabetes peer support intervention provided the model for the group and telephone peer contacts undertaken in this intervention for HF.

Patients were recruited from a local community hospital and randomly assigned to either a Peer Support or Nurse Practitioner Care Management arm. Those in the Nurse Practitioner Care Management arm received a one-time nurse practitioner-led HF SM group session, encouragement to follow-up with the HF NP, and educational materials. Those in the Peer Support arm participated in the program consisting of three components: group sessions, peer partner telephone calls and educational materials. Participants completed quantitative assessments at baseline and at 6 and 12 months follow-up.

Heart failure NPs first led group sessions to provide information and allow interaction among patients with HF at a local community hospital immediately after randomisation, and then 1, 3, and 6 months post-randomisation. Second, participants were matched with other participants to help each other as peer partners and provided with a no-cost telephone system that would automatically connect them to their peer partner using interactive voice response (IVR) technology. The system recorded call initiation, frequency, and duration, set time periods in which calls could be blocked, and also generated automated reminders every 7 days if no calls were attempted. The system also enabled participants to leave voice messages for research staff or HF NPs. Participants were encouraged to talk at least weekly with their peer partners. Finally, participants received educational materials including a workbook containing information on meal plans, ways to reduce sodium intake, and guided worksheets with action-planning tools and a DVD illustrating the ways in which peer telephone contacts could be used to support SM efforts. In order for home-bound patients to participate in the program, all materials were mailed to them and they were offered an individual telephone, rather than face-to-face, orientation to the program components.

Participants engaged in a reciprocal peer support program when they made successful connections with their peer partners. Participants experienced the comfort of hearing others describe feelings and experiences that they shared. Additionally, they received valuable information and practical tips offered by others facing similar HF challenges. Illness, depression, and ineffective pairings were described as barriers to participation.

Of note, in this study was that most participants who developed a successful pairing said that their personalities just ‘clicked’ and that they could not say why they really got along with their peer.

Lochart et al. (2014) acknowledge that because the peer relationship can be so supportive when it works well, learning which factors are associated with effective partnerships is an especially important area for future investigation.

An earlier and similar pilot study was conducted by Heisler et al. (2007). They too undertook an intervention using telephone peer support. In this pilot, the authors evaluated the feasibility and acceptability of an interactive voice response (IVR)–based platform to facilitate telephone peer support among older adults with HF. Participants completed a baseline survey, were offered a 3-hour training session in peer communication skills, and were paired with another patient who had HF. Participants were asked to contact their partner weekly using a toll-free IVR phone system that protected their anonymity and provided automated reminders if contacts were not made. Times and duration of participants’ telephone contacts were monitored and recorded. After the 7-week intervention, participants completed surveys and brief face-to-face interviews. The authors found high levels of use and satisfaction and improvements in depressive symptoms among the 20 pilot study participants. The authors further report that an IVR peer-support intervention is feasible, is acceptable to patients, and may have positive effects on patients’ HF social support and health outcomes, in conjunction with structured health system support,

Based on their earlier pilot study Heisler et al. (2013) conducted a randomised controlled trial. Using the same methods and preparation as the pilot study, findings from the RCT were disappointing. The researchers concluded that one-on-one peer support telephone calls between sex-matched partners with HF supplemented with periodic NP-facilitated group sessions provided no incremental benefit to enhancing access to HF NCM in a community hospital health system. The major explanation seems to be lack of engagement in the intervention, as only a minority of patients with HF randomised to the peer support arm participated in a meaningful way with either the peer telephone calls or group sessions. Identifying methods to engage this population in behaviour change and social support interventions, as well as identifying subgroups of HF populations who are candidates for peer support and other behavioural interventions, remain a high priority.

Bakan & Akyol (2007) report on a study to examine the effects of a Roy Adaptation Model-based experimental education, exercise and social support programme on adaptation in persons with heart failure.

A booklet for patient training was given to those in the intervention group. Participants received a patient identification form, assessment form for physiological data, the Minnesota Living with Heart Failure Questionnaire, Interpersonal Support Evaluation List and the 6-Minute Walk Test. The intervention programme consisted of two one-to-one counselling sessions (clinical appointments) with patients, two phone calls and one group meeting over a 3-month period.

Clinical appointments included one-to-one patient counselling and HF education by the researchers At the first appointment each patient in the intervention group was given a booklet, titled ‘How Can I Learn to Live with Heart Failure’, developed by the investigator. This included information on medications; definition of HF; symptoms; types of exercise; the walking schedule for the programme; important points on diet; a sample diet list; cholesterol; liquid intake; tobacco and alcohol consumption; and contact details for the clinic. Patients were also given a crossword puzzle about HF; a schedule of appointment and education sessions; and a calendar on which to record weight on a daily basis. The booklet focuses on supporting patients in adhering to their treatments, adjusting medications and doing exercise.

Patients in the intervention group adapted well to their condition and the four adaptive modes of Roy Adaptation Model were interrelated. Patients’ quality of life was enhanced, their functional capacities increased and social support within the interdependence dimension improved in patients in the intervention group.

LaFramboise et al. (2009) study set out to determine perceptions about ease of use, efficacy and difficulties encountered by patients who used an in-home tele-health communication device, known as Health Buddy. Use of tele-health technology can provide an economical, timely means of monitoring and educating large numbers of individuals for improved health outcomes.

The Health Buddy is a 6x9-inch device, with a liquid crystal display screen and 4 buttons that attach to the telephone line. Participants using the Health Buddy were asked 7 questions daily about heart failure symptom status and ability to follow the prescribed regimen. To respond to the questions or statements, the participant simply had to push 1 of 4 large buttons on the front of the box. When all of the questions are answered and educational messages reviewed, the Health Buddy gives the option of reviewing answers (in case they believed they had made an error) or ending the session. Health Buddy content is programmed via computer using special software and transmitted to the Health Buddy through the telephone line. Once the participant's responses have been downloaded from the Health Buddy to a central computer, a health-care professional can view the responses and determine the need for intervention.

Only a few participants in this study ever needed to speak with the research nurse who monitored Health Buddy responses. The only contact most participants using the Health Buddy had was with the research assistant who came to their home for data collection at the 4 data collection time points.

Participants perceived social support from the Health Buddy despite the fact that they had infrequent or no human contact during the intervention. Categories within the supporting theme include (1) feeling cared for and watched over, (2) social contact, and (3) a lifesaver.

Many participants perceived the daily interaction with the Health Buddy as a social contact and something they looked forward to as well as something to do daily.

Yu et al. (2009) study looked at improving health-related quality of life of patients with chronic heart failure through the use of relaxation therapy. This experimental intervention was a relaxation training programme conducted by a research nurse trained in relaxation therapy. The authors inform that progressive muscle relaxation training (PMRT) improves the mood status, exercise capacity and autonomic regulation of patients with CHF.

The intervention involved two weekly training sessions for PMRT and one skill revision workshop held 4 weeks afterwards. Participants were required to undertake twice daily PMRT self-practice at home for 12 weeks after the training session. Each participant was provided with a PMRT picture guide, tape-recorded PMRT instructions and a cassette player to facilitate the extended self-practice. The research nurse also initiated six bi-weekly telephone calls to clarify any misconceptions the participants might have had and reinforce their adherence.

These authors conclude that a single relaxation technique with an extended self-practice improves the health-related quality of life of Chinese older people with congestive heart failure. Its effect in enhancing their psychological and social well-being is most prominent. Strategies such as making regular follow-up telephone calls, discussing the experience of relaxation and offering clarification, and assisting patients to incorporate relaxation practice into their daily lives may be effective in ensuring successful delivery of relaxation training. Relaxation therapy can be integrated into home-based models of care to enhance the health outcomes of patients with chronic heart failure.

Hart-Wright et al. (2006) described their intervention as non-pharmacological nursing intervention, known as LINK. LINK was a telephonic support programme for patients with HF to prevent or minimise exacerbations that lead to unnecessary hospitalisations. The programme provided support and education (although the details of these are not explicit within the paper), but were developed to empower patients to implement modest behavioural modifications. Analysis included 316 patients with a mean length of stay of 79 days. Comparison of Acute Care Days (ACDs) prior to and after LINK enrolment showed a 69% reduction from 1291 days to 398 days respectively. Emergency department visits improved from 156 prior to LINK to 98 after LINK: a 37% reduction.

The authors state that LINK had an effect on patient outcomes as it had improved healthcare access via the telephone system to an experienced HF nurse working to triage patients to essential resources, individualised and consistently reinforces education on recognising symptom onset and improves patient's competency in self-management of their disease.

Patient needs and experience

Heisler et al. (2007) suggest that from the qualitative comments from participants, peers are most effective in providing support and reinforcement rather than assistance in goal setting and achieving targeted goals.

Matching of peer support pairs could be important factor in peer support interventions – Heisler et al. (2007) matched on the basis of similarity between goals. Lockhart et al. (2014) did not actively study this variable, participants within interviews stated that they did compare themselves to other participants and this had a powerful impact.

What was an interesting finding in terms of this systematic review, was the participants perceived social support from Health Buddy despite having very infrequent or no human contact during the intervention. Categories within this theme of 'supporting' were: 1. Feeling cared for and watched over; 2. Social contact; 3. A lifesaver, as demonstrated below in the corresponding quotes:

1. "It was sort of like having a healthcare provider come into your house every day. And it was a great thing emotionally."
2. "[The Health Buddy] is something to do every day; in fact, I looked forward to it."
3. I wouldn't be here today if it wasn't for that little Health Buddy because it set me on the right path again in my life."

None of the papers within this review explicitly measured patient needs, and the measurement of patient experience was variable therefore making comparison between interventions impossible.

Impact on health and/or social outcomes

In the study by Bakan and Akyol (2007), the RCT demonstrated a number of statistically significant effects on outcomes: The intervention group had improved scores in the MLWHF (Minnesota Living with Heath Failure Questionnaire) scores in the physical dimension and emotional dimension. There was a statistical significant increase in the 6-minute walking distance compared with baseline at 3 months for the intervention group. There was a statistical significant decrease in the 6-minute walking distance compared with baseline at 3 months for the control group. Intervention group showed a statistically significantly improved Interpersonal Support Evaluation List total score and over time compared to control group. There was no inter-group difference in quality of life measures. However the quality of this RCT should be noted when considering the reliability of the results (e.g. no power calculation in sampling; no blinding; no detail of randomisation; no loss to follow up detail).

Dickson et al. (2014), in a RCT study, demonstrated that there was significant improvement in self-care maintenance, self-care management and heart failure knowledge in the intervention group compared to the control group following a skill-building intervention. There was no significant difference in quality of life measures. The authors conclude that an intervention in a community setting by lay health educators provides an alternative to clinic or home based teaching, and may be useful in diverse populations and geographically varied settings.

Using a relaxation therapy within a RCT, Yu et al. (2009) demonstrated that those who attended a relaxation training programme reported statistically significant great improvement in psychological and social health-related quality of life than those in the control group. However, these improvements were seen most notably at the 8-week time point but this benefit was not maintained over time.

In a RCT (Heisler et al. 2013) comparing heart failure nurse practitioner input (control group) with heart failure nurse practitioner input with a Reciprocal Peer Support (RPS) programme (intervention group) to patients with heart failure. Only 55% of RPS participants took part on any peer calls. The groups did not differ in hospitalisation rates or mortality rates, and therefore the RPS programme did not improve outcomes when compared to heart failure nurse practitioner input alone.

The one quantitative study (Hart-Wright et al. 2006) that was included used a telephonic support program for patients (n=316) with HF to prevent or minimise exacerbations that lead to unnecessary hospitalizations through support and education. The main focus of the program was to support and empower patients to modify their lifestyle and encourage timely medical interventions. The research methodology is unclear in the report, but findings claim that the program reduced length of stay in hospital from 1291 to 398 days (69% reduction) and emergency department attendance from 156 to 98 (37% reduction) after its introduction.

3.3 Overview of findings

The evidence (although not strong) above would suggest that:

- Tele health devices may be of use for social support
- Peer support groups may be more beneficial if peers are matched (although the method of matching is not evidence based in terms of what is best practice)
- Lay health educators combined with social support programmes may be a model worthy of further testing
- Reliability and Validity testing needs to be further developed on this population with measurement tools (e.g. Minnesota Living with Heath Failure Questionnaire, QOL measures)
- When an intervention comes to an end, there should be a period of transition for the user (and this should be evaluated)
- A number of outcomes could be measured when evaluating a formalised social intervention (FSI) in the future (e.g. Social isolation; Social support; Health outcomes; Admission rates to hospital; Anxiety and depression scales; Compliance/adherence with medication and other health interventions/advice; Mortality rates; Satisfaction rates; Patient experience questionnaire and exploration). There is no strong evidence that FSIs can affect any of those outcomes, either positively or negatively.
- Baseline measurements should be established before any intervention is undertaken.

- Online social support may be useful particularly where the discussions can be moderated by a health expert who can help assess and control the quality of the information. However the evidence on this is very limited.

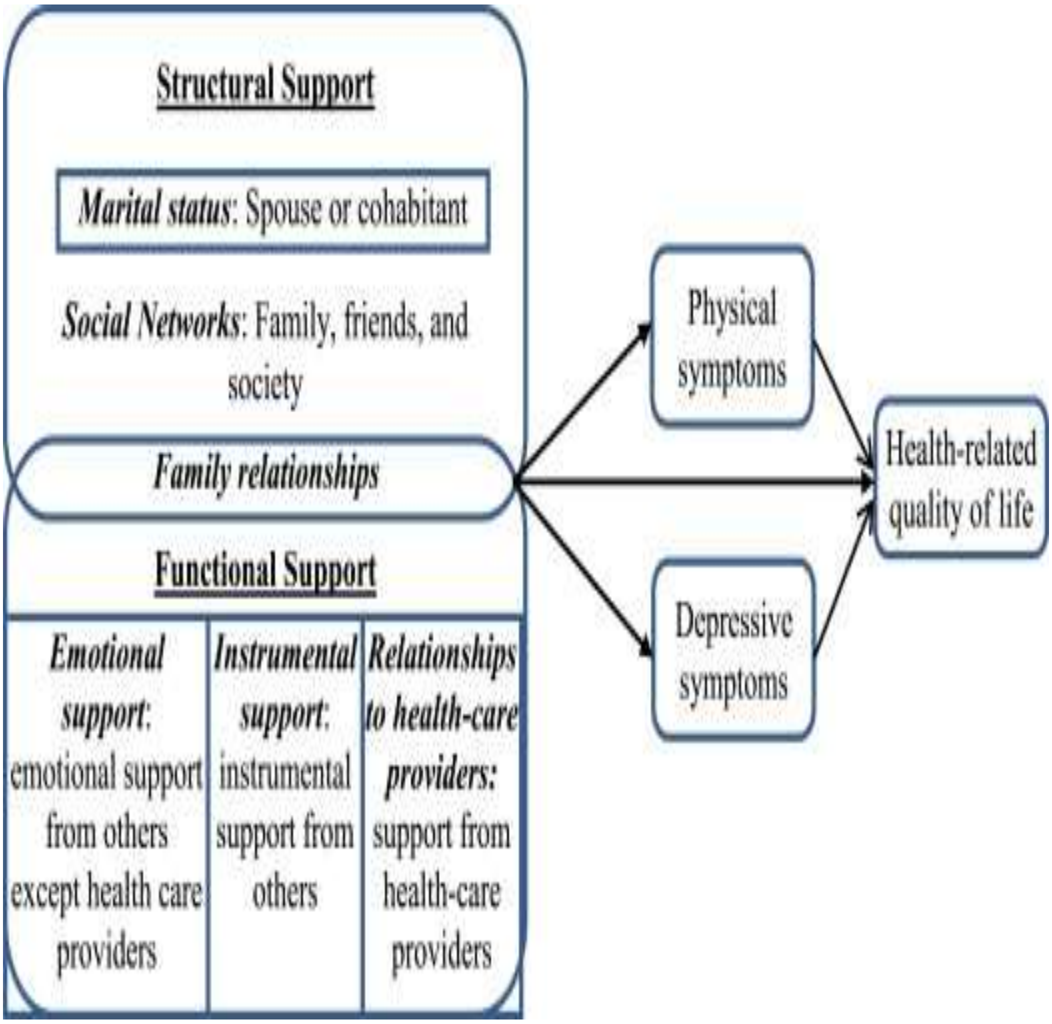
4.1 Discussion

There were nine studies included in this review which comprised of four Randomised Control Trials (RCTs), one quantitative study, one mixed method study and two qualitative studies and one literature review. The quality of RCTs can be described as low as a consequence of risk of bias. Studies using other methods were of similarly low methodological rigour. Given the small number of studies included in the review allied to the existing evidence that loneliness has been found to double mortality from circulatory illness (Patterson and Veenstra 2010), there is a need for further high quality intervention studies.

Social support in heart failure studies has been conceptualised in many ways, ranging from structural support such as, marital status to more extensive combinations of structural and functional support (Heo et al. 2014). This reflects the broader literature around social support in which different conceptualisations makes it difficult to compare results of interventions. We have concluded that any formalised intervention and its developmental process should be described in greater detail for the purposes of dissemination, uptake and study replication.

A small number of evaluation studies and intervention developments have used an explicit theoretical conceptual model which both strengthens the quality of a study and leads to interventions which can achieve better patient outcomes. Wilson and Clearly's model proposes that social support may be associated with heart disease symptoms and HRQOL (Ferrans et al. 2005). We suggest that the theoretical framework developed by Wilson and Clearly (1995) and employed by Heo et al. (2014) should be employed in any future research (Figure 2). However given the other health outcomes mentioned previously we suggest further development of the model to include a wider range of outcomes rather than just HRQoL.

Figure 2: Social Support and Heart failure Symptoms (Wilson and Clearly 1995)



A major limitation, not confined to heart failure, is the large number of poorly described social support-loneliness interventions that can be found in the literature ranging from Men's Sheds to Befriending/Transitional Discharge models (Reynolds et al. 2004). Few, if any, have been developed using a framework such as the MRC Complex Intervention process (MRC 2008). This review can be viewed as part of the intervention development phase for a social support intervention in heart failure which will be embedded within with existing services for this patient group. Viewing an intervention in heart failure as a complex intervention would indicate that this be evaluated using a number of research methods and would overcome the low quality of research design found in the review. The MRC approach would also accommodate a key design problem found in the Transitional Discharge intervention with Mental Health problems which included a befriending element. This relates to the lack of fidelity in implementation of the intervention (Sharkey et al. 2005).

There were a number of settings used within the studies of this systematic review, and future studies should consider the context of the intervention. For example, cardiac rehabilitation (CR) has been shown to improve health behaviours and risk factors and the evidence suggests that home CR is as effective as hospital-based CR (Munro et al. 2013). Whilst there have been few studies of home based cardiac rehabilitation they suggest that it is acceptable, safe and effective (Munro et al. 2010). It is known though that although research and clinical guidelines recommend that heart failure patients are given cardiac rehabilitation (Ades et al. 2013; British Association for Cardiovascular Prevention and Rehabilitation, 2012; Scottish Government, 2009), the reality is that very few are enrolled due to funding / resource issues and exclusion from local commissioning agreements (Dalal et al. 2012).

It is suggested by the Scottish Government (2012) that heart failure specialist nurses could provide psychological support as part of routine management of patients with heart failure but the efficacy and feasibility of this needs exploration.

The Better Heart Disease and Stroke Care Action Plan (Scottish Government, 2012) suggests that to alleviate social isolation in heart failure patients that each health board in Scotland should consider adopting through the Cardiac Managed Clinical Networks the initiative by Chest, Heart and Stroke Scotland where befriending services, educational forums and a newsletter are incorporated in a heart failure support service.

Internet based communities may also be considered for inclusion in any future intervention, but there is very limited evidence on this, and the use of a health expert as moderator (or not).

A further element of a future multi-layered intervention would include peer emotional support groups. These may be more beneficial if peers are matched although the method of matching is not evidence based in terms of what is best practice. Lay health educators combined within social support programmes may be a model worthy of further testing.

We would argue that a disease specific measure of HRQoL has many advantages over a more general measure. The Minnesota Living with Heart Failure Questionnaire has been employed in exploring the link between social support and HRQOL in heart failure (Heo et al. 2014). The MacNew heart disease health-related quality of life instrument (Dixon et al. 2002) is another disease specific measure. A small study testing the validity and reliability of these may be beneficial.

5.1 Conclusion

This review has highlighted a number of limitations in the existing literature on formalised social support interventions in heart failure. There is currently no ‘gold standard’ off the shelf interventions for service providers. We have outlined a model for intervention design and a research framework to further develop and evaluate such an intervention.

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Appendix 1: Data Extraction Summaries of Included Studies

Bakan G and Akyol AD (2008) Theory-guided interventions for adaptation to heart failure. Journal of Advanced Nursing, 61 (6), pp. 596-608.

Dickson VV, Melkus GD, Katz S, Levine-Wong A, Dillworth J, Cleland CM and Riegel B (2014) Building skill in heart failure self-care among community dwelling older adults: Results of a pilot study. Patient Education and Counseling, 96 (2), pp. 188-196.

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Hart-Wright J, Patrick S, He H, Green J, Rierson M, Teal G, Dawson J and DeSilva, B (2006) Effectiveness of a nurse-led telephonic support program for heart failure patients. Progress in Cardiovascular Nursing, 21 (2), pp. 111-111.

Heisler M, Halasyamani L, Cowen ME, Davis MD, Resnicow K, Strawderman RL, Choi H, Mase R and Piette JD (2013) Randomized controlled effectiveness trial of reciprocal peer support in heart failure. Circulation.Heart Failure, 6 (2), pp. 246-253.

Heisler M, Halasyamani L, Resnicow K, Neaton M, Shanahan J, Brown S and Piette JD (2007) "I am not alone": the feasibility and acceptability of interactive voice response-facilitated telephone peer support among older adults with heart failure. Congestive Heart Failure (Greenwich, Conn.), 13 (3), pp. 149-57.

LaFramboise LM, Woster J, Yager A and Yates BC (2009) A technological life buoy: patient perceptions of the Health Buddy. Journal of Cardiovascular Nursing, 24 (3), pp. 216-224.

Lockhart E, Foreman J, Mase R and Heisler M (2014) Heart failure patients' experiences of a self-management peer support program: A qualitative study. Heart & Lung, 43 (4), pp. 292-298.

Yu D, Lee D and Woo J (2010) Improving health-related quality of life of patients with chronic heart failure: effects of relaxation therapy. Journal of Advanced Nursing, 66 (2), pp. 392-403.

Data Extraction Template

Title of Article	Theory-guided interventions for adaptation to heart failure
Year of Publication	2007
Author(s)	Bakan G, and Akyol A.
Journal Name	Journal of Advanced Nursing
Country of research	Turkey
Volume/Issue	61 (6)
Methodology	RCT
Focus, aims or objectives	Aim: to investigate the effects of a Roy Adaptation Model-based experimental education programme on heart failure patients.
Outcome measure(s)	Body mass index, plasma cholesterol level.
Methods	The study was conducted at a polyclinic. Ethical approval: institutional approval gained. Data collection: collected via a survey. Data analysis: correlations examined using Pearson's Product Moment correlation coefficients. Also, chi-square and t-tests were used.
Sample strategy/size	Convenience sample n=43: 21 intervention group, 22 control group
Validated evaluation measures	Minnesota Living with Heart Failure Questionnaire Interpersonal Support Evaluation List – short form 6-minute walking test
Formalised Social Intervention(FSI)	The intervention programme consisted of education, exercise and social support. The programme consisted of 2 x individual counselling sessions, 2 x telephone calls and a group meeting over a 3-month period. Participants were encouraged to attend with their spouse, partner.
Cause(s) of Loneliness	Not known from this publication
Patient needs if lonely	Not known from this publication
Impact of FSI on health outcomes	It is reported that the intervention group had an improvement in their QoL. Participants with higher levels of social support are more physically well.
Impact of FSI on function outcomes	The intervention group had a significant improvement in the 6-minute walking test.
FSI – influence on knowledge of condition	Not known from this publication
FSI – influence on engagement with self-care	Not known from this publication
Results	The Roy Adaptation Model-based experimental

	education programme can guide healthcare professionals when supporting those with heart failure.
Grade	Low
Include or Exclude	Include
Comments	The improvements noted in relation to health and functional outcomes cannot be attributed solely to the FSI as the intervention programme also included an exercise component. While the FSI was facilitated by healthcare professionals, there was group based activity and so this study should be included although its contribution may be minimal.

Data Extraction Template

Title of Article	Building skill in heart failure self-care among community dwelling older adults: Results of a pilot study
Year of Publication	2014
Author(s)	Dickson V, Melkus G, Katz S, Levine-Wong A, Dillworth J, Cleland C, and Riegel B.
Journal Name	Patient Education and Counseling
Country of research	USA
Volume/Issue	96
Methodology	Quantitative - RCT
Focus, aims or objectives	Aim: to pilot test the efficacy of a community-based skill-building intervention on heart failure self-care.
Outcome measure(s)	Self-care Knowledge Health related quality of life (QoL)
Methods	Ethical approval: institutional approval gained. Recruitment: Participants were invited to participate by means of poster advertisements and through referral from clinicians. Randomisation: participants were randomised to an intervention group or to a 'wait-list group' who waited 3 months to have the intervention. Data collection: data collected at 3 time points: baseline, 1 and 3 months. At baseline sociodemographic data was collected. Surveys listed below were administered at all time points. Data analysis: descriptive statistics used to describe sociodemographic data. Chi-square, independent samples t-tests and analysis of variance used to examine differences between baseline and other time points.
Sample strategy/size	Convenience sample was recruited from cardiology clinics in one geographical area. A power calculation was used to determine the sample size to detect a significant difference between intervention and control groups. Of 250 individuals with heart failure, 144 met the inclusion criteria. Of those n=75 participants were subsequently enrolled and randomised: Intervention group n=38 Control group n=37 56 participants completed the study. Reasons for

	attrition were: lost to follow up and changes to participants' personal circumstances.
Validated evaluation measures	Self-Care of Heart failure Index Dutch Heart Failure Knowledge Scale Kansas City Cardiomyopathy Questionnaire Charlson Co-morbidity Index Duke Activity Status Index NYHA heart failure classification
Formalised Social Intervention(FSI)	Community-based skill-building intervention. This focussed on building essential self-care behaviours and skills in effective symptom monitoring. The FSI was delivered by a 'lay' health educator in community 'seniors centres'. The 'lay health educator' was educated to degree level in health education. Groups were between 4 and 8 participants who met twice weekly for around one hour. This continued for 4 weeks. All intervention sessions were audio-recorded and transcribed verbatim to ensure the health educator adhered to the study protocol.
Cause(s) of Loneliness	Not known from this publication
Patient needs if lonely	Not known from this publication
Impact of FSI on health outcomes	No significant difference was found in health related QoL between control and intervention groups.
Impact of FSI on function outcomes	Not known from this publication
FSI – influence on knowledge of condition	The intervention group were statistically more knowledgeable about their condition compared with the intervention group (p=0.001).
FSI – influence on engagement with self-care	Improvements noted in self-care at both 1 month and 3 month time points. Self-care maintenance (medication / dietary adherence / symptom monitoring) was statistically improved in the intervention group (p=0.041) when compared with the control group. Significant improvement was also found in self-care management (symptom recognition / evaluation / treatment in the intervention group, again, in comparison with the control group (p=0.024
Results	No significant difference between intervention and control groups at baseline noted in relation to self-care maintenance / management and knowledge. Health related QoL was however, higher in the control group.
Grade	High
Include or Exclude	Include
Comments	This study will help to address several of the objectives for the systematic review.

Data Extraction Template

Title of Article	Effectiveness of a nurse-led telephonic support program for heart failure patients
Year of Publication	2006
Author(s)	Hart-Wright J, Patrick S, He H, Green J, Rierson M, Teal G, Dawson J, and DeSilva B.
Journal Name	Progress in cardiovascular Nursing
Country of research	USA
Volume/Issue	Spring
Methodology	Quantitative
Focus, aims or objectives	AIM: To evaluate the effectiveness of a telephonic support system in reducing hospital readmission rates
Outcome measure(s)	Hospital readmissions
Methods	No information given regarding ethical approval, recruitment, how the data were analysed Participants had used the LINK programme for more than 31 days. It is assumed that data were collected from hospital records but that is not apparent. The data collected were the number of days in hospital (termed acute care days) and the visits to the emergency department both before and after the patient participated in the LINK programme.
Sample strategy/size	n=316. No information given regarding the sampling strategy
Validated evaluation measures	None used
Formalised Social Intervention(FSI)	LINK – a telephonic support system
Cause(s) of Loneliness	Not known from this publication
Patient needs if lonely	Not known from this publication
Impact of FSI on health outcomes	Not known from this publication
Impact of FSI on function outcomes	Not known from this publication
FSI – influence on knowledge of condition	Not known from this publication
FSI – influence on engagement with self-care	Not known from this publication
Results	Comparisons were made from before the LINK programme support to after and it was found that there was a substantial reduction (69%) in acute care days. Also, there was a 37% reduction in visits to the emergency department.
Grade	Low
Include or Exclude	Include
Comments	Scant information about this study in the publication. Essentially, it is written as an abstract. The details of the telephone support programme are missing.

	It does though help to address at least one of the objectives of the systematic review.

Data Extraction Template

Title of Article	Randomised controlled effectiveness trial of reciprocal peer support in heart failure
Year of Publication	2013
Author(s)	Heisler M, Halsyamani L, Cowen ME, Davis MD, Resnicow K, Strawderman RL, Choi H, Mase MSW, Piette JD
Journal Name	Circulation Heart Failure
Country of research	USA
Volume/Issue	6
Methodology	Quantitative – RCT
Focus, aims or objectives	Aim: To Test effectiveness of intervention in patients with Heart Failure
Outcome measure(s)	First hospitalisation or death.
Methods	Ethical approval: Given by institutional review board. Recruitment: At inpatient unit and HF clinic. Data collection: pre intervention, 6 month survey, 12 month primary outcomes Data analysis Intention to treat, cox regression model
Sample strategy/size	Random sample n=136 intervention + 131 control 1.
Validated evaluation measures	Minnesota living with heart failure Diabetes social support scale adapted for HF
Formalised Social Intervention(FSI)	Case manager training for nurse practioner Nurse practitioner care management 1.5 initial meeting and offer of support Reciprocal peer support group, 3 hour session, weekly phone call, offer 3 x 1.5 hr optional session with nurse practitioner
Cause(s) of Loneliness	Does not deal with loneliness but sees social support leading to better self-care
Patient needs if lonely	Not known from this research publication
Impact of FSI on health outcomes	No difference in primary outcomes.
Impact of FSI on function outcomes	
FSI – influence on knowledge of condition	Not known from this research publication
FSI – influence on engagement with self-care	More than half patients in intervention group had little of no engagement in peer support element
Results	No difference in primary measures
Grade	high
Include or Exclude	Include
Comments	Complex and probably high costs intervention. Poor level of engagement in HF groups needs to be considered in any future intervention

Data Extraction Template

Title of Article	"I am not alone": The feasibility and acceptability of interactive voice response-facilitated telephone peer support among older adults with heart failure
Year of Publication	2007
Author(s)	Heisler M, Halasyamani L, Resnicow K, Neaton M, Shanahan J, Brown S, and Piette J.
Journal Name	LE JACQ
Country of research	USA
Volume/Issue	May / June
Methodology	Mixed method
Focus, aims or objectives	Aim: To assess the feasibility of interactive voice response (IVR) facilitated peer-support among patients with heart failure living in the community. To evaluate participants' experiences of using the IVR To explore changes in participants behaviour, self-efficacy and depression.
Outcome measure(s)	
Methods	Ethical approval: not mentioned. Recruitment: potential participants were informed of the study when visiting a heart failure nurse practitioner and were subsequently mailed a letter of invitation. Participants were matched to another participant based on the heart failure self-management goals they identified at baseline. Participants were incentivised to participate and received monetary gifts on completion of the baseline survey and after the final survey. Data collection: data were collected at baseline and then again after using the IVR for 7 weeks. Participants were also interviewed at the end of the intervention (semi-structured interviews). Data collected included socio-demographics, depressive symptoms, heart failure self-efficacy, heart failure self-management behaviours. Data analysis: descriptive statistics and paired t-tests.
Sample strategy/size	Letters were sent to 49 patients and of those, consent to take part was given by 23, who subsequently completed the baseline survey. 20 participants completed the intervention.
Validated evaluation measures	Centre for Epidemiologic Studies Short Depression

	Scale Perceived Competence Scale
Formalised Social Intervention(FSI)	The IVR was adapted from a prototype used successfully in a pilot study. The FSI consisted of an initial face-to-face training session on how to use the IVR. Thereafter, a 2.5 hour interactive training session on motivational interviewing was given and this was led by an expert on that topic. Written material that accompanied the session was given to the participants. Participants were asked to contact their partners at least once per week. A website was used to monitor the calls. Reminders were given if partners failed to make contact. After 3 weeks, the study coordinator contacted all participants to ascertain their experience of using the IVR.
Cause(s) of Loneliness	Not known from this publication
Patient needs if lonely	Not known from this publication
Impact of FSI on health outcomes	Significant improvement was noted in participants' depressive symptoms over the course of the programme.
Impact of FSI on function outcomes	Not known from this publication
FSI – influence on knowledge of condition	Not known from this publication
FSI – influence on engagement with self-care	70% found the FSI helpful in managing heart failure symptoms. 60% thought that their partner had helped them improve their heart failure self-management. Despite this, there was little change in self-reported self-management between baseline and study conclusion.
Results	All 20 participants spoke once per week for at least two weeks of the study duration. 94% of participants found the initial information giving sessions helpful. 100% were confident that they could use effective listening. Participants reported that they had used motivational interview techniques during the peer contact. Participants thought the programme helped to foster camaraderie and was helpful in affording the opportunity to help others. Many participants referred to their partner as a 'new friend'. Although participants enjoyed the telephone contact, many admitted that they had had little effect on their self-management of heart failure. There was a desire for face-to-face meetings with partners and greater support from healthcare providers.
Grade	Low

Include or Exclude	Include
Comments	This study helps to address some of the objective of the systematic review.

Data Extraction Template

Title of Article	A technological life buoy – patient perceptions of the Health Buddy
Year of Publication	2009
Author(s)	LaFramboise L, Woster J, Yager A, and Yates B.
Journal Name	Journal of Cardiovascular Nursing
Country of research	USA
Volume/Issue	24 (3)
Methodology	Qualitative
Focus, aims or objectives	In relation to a tele-health intervention, the study sought to explore the ease of use, the efficacy of this and any difficulties encountered when using it.
Outcome measure(s)	
Methods	Ethical approval: Approval given from the institution where the research was conducted. The study began 6 months after the completion of the parent study and this meant participants had finished using the 'Health Buddy' anywhere between 6 months and 2 years before participation in this study. Of the 13 participants recruited, 8 had used the Health Buddy only and 5 had used the Health Buddy and also received home visits from healthcare professionals. Participants were incentivised to participate. Data collection: A combination of focus groups and individual interviews were used to collect data. Focus groups had 3 or 4 participants in each. An iterative process was used to refine the questions for the focus groups / individual interviews. What informed these questions is not apparent. Verbatim transcripts produced of interviews / focus group discussions. Data analysis: QSR N5 software package for qualitative data analysis. Data subject to thematic analysis. Member validation used to check transcripts.
Sample strategy/size	Purposive sample drawn from a larger RCT. Two groups of participants recruited: Those who had used the tele-health programme for >30 days but had not completed the full 6 month programme and secondly, a group of those who had completed the whole 6 month programme.

Validated evaluation measures	
Formalised Social Intervention(FSI)	'Health Buddy' tele-health communication device. Device allowed daily capture of participants' heart failure symptom status and ability to follow prescribed treatment regime. That data was downloaded to allow a healthcare professional to review the participants' responses. The device also gave educational messages
Cause(s) of Loneliness	Not known from this research
Patient needs if lonely	Not known from this research
Impact of FSI on health outcomes	Fewer readmissions to hospital or major cardiac events noted.
Impact of FSI on function outcomes	Not known from this research
FSI – influence on knowledge of condition	Improved participants knowledge by giving short educational messages daily. Information was repeated to allow reinforcement of key messages. Messages were consistent with the information participants received from healthcare professionals.
FSI – influence on engagement with self-care	The FSI gave reminders about treatment adherence. It motivated participants to monitor and manage their heart failure and this enhanced their self-management.
Results	On completion of the FSI programme, some participants continued their habitual self-management routine but the study found that other participants had less effective self-management. Participants perceived that the reminders given by the FSI were helpful for enhanced self-management. Using the Health Buddy FSI made participants feel 'cared for and watched over' and was considered to be a social contact despite no human interaction. The prompts for symptom status were considered repetitious, boring and pointless by some participants.
Grade	Low
Include or Exclude	Include
Comments	The Health Buddy was easy to use, took only a short time to complete the interaction and could be done at a time convenient to the participant. Sample size for the study was small even for a qualitative study and so the results are difficult to generalise to the wider heart failure patient population.

	The time lapse between using the Health Buddy and collecting data for the study varied from 6 months to 2 years and so the findings may be biased due to poor participant recall about the use / benefits of using this tele-health device.

Data Extraction Template

Title of Article	Heart failure patients' experiences of a self-management peer support program: A qualitative study
Year of Publication	2014
Author(s)	Lockhart E, Foreman J, Mase R, and Heisler M.
Journal Name	Heart & Lung
Country of research	USA
Volume/Issue	43
Methodology	Qualitative – grounded theory
Focus, aims or objectives	Aim: to explore the experiences of heart failure patients in a heart failure self-management support programme. Objectives: To identify factors that influence the effectiveness of the programme. To understand how participation in the programme affected heart failure self-management. To identify barriers / facilitators to programme participation.
Outcome measure(s)	None identified.
Methods	This research was conducted as a sub-study of the 'Buddy study'. Ethical approval: Approved by the institutional review board. Recruitment: Consent was sought immediately before each interview. Data collection: semi-structured interviews were conducted to collect data from participants 6 months after they had completed the 'Buddy Study' intervention. Data management: Interviews were audio-recorded and transcribed verbatim. Themes were identified and techniques used in grounded theory were used (inductive identification / revision of themes / constant comparison / data saturation).
Sample strategy/size	37 patients were invited to participate and ultimately the sample consisted of 28 participants Purposive sampling of patients engaged (n=18) / non-engaged (n=10) in 'buddy study' intervention.
Validated evaluation measures	None used.
Formalised Social Intervention(FSI)	Study Buddy intervention. Details of this are scant but it seems to consist of group meetings, regular

	peer contact by telephone, an information DVD and a workbook on goal setting and action planning
Cause(s) of Loneliness	Inadequate emotional support from medical staff.
Patient needs if lonely	The ability to talk and share experiences with other heart failure patients. To feel that they are not alone in dealing with their heart failure. Emotional support.
Impact of FSI on health outcomes	A perceived risk of becoming depressed if the peer support person is depressed.
Impact of FSI on function outcomes	Peer interaction enhanced patients' confidence and that improved their functional status. The ability of participants to compare themselves with others with heart failure gave a sense that they were better off and that enhanced functional ability.
FSI – influence on knowledge of condition	Peer interaction from other heart failure patients was considered to be a source of additional information that helped them improve their self-management. The information from the Buddy study was easy to understand and helped the participants to more effectively manage their heart failure.
FSI – influence on engagement with self-care	Peer interaction had a positive influence on self-management behaviours such as weight monitoring and adhering to dietary restrictions in relation to salt and fluid intake. Greater independent living.
Results	Emergent themes include: heart failure specific peer support, friendship, information exchange, low functional health status. Themes relevant to 'engaged' participants were interpersonal (friendship and exchanging information with others). Factors particular to the individual informed themes from those considered 'not engaged' (i.e. low functional health status). The peer interaction groups varied in size with some only having 2 participants and that was felt to affect the opportunity for peer interaction. Several participants failed to engage with their assigned peer due to difficulties with the relationship or perceived poor functional status.
Grade	Low

Include or Exclude	Include
Comments	This study was conducted as a sub-study of the ‘Buddy Study’ research. The intervention that is explored in this study is not described and so it would be appropriate to source publications related to the Buddy Study to ascertain what the FSI consists of. Most participants made use of the peer interaction group meetings. It is reported that few watched the educational DVD or use the workbook. The educational materials were considered to be of poor value. The sample wad dominated by participants who had engaged with the ‘Buddy study’ intervention and this may have skewed the findings. Non-engaged patients were difficult to recruit.

Data Extraction Template

Title of Article	Health social networks as online life support groups for patients with cardiovascular diseases
Year of Publication	2013
Author(s)	Medina el, Filho OL, Mesquita CT
Journal Name	Arquivos Brasileiros de Cardiologia
Country of research	Brazil
Volume/Issue	101(2)
Methodology	Review, really description of 4 interventions
Focus, aims or objectives	Aim: Reporting the results of literature on the use of on-line support groups
Outcome measure(s)	Improved social life, emotional support, morbidity, diet, medical visits
Methods	Lit review
Sample strategy/size	4 papers
Validated evaluation measures	Patient experience of on line support
Formalised Social Intervention(FSI)	on line support both moderated and un moderated
Cause(s) of Loneliness	Does not deal with loneliness
Patient needs if lonely	Not known from this research publication
Impact of FSI on health outcomes	Problems for patients with analysis and managing large amounts of data
Impact of FSI on function outcomes	
FSI – influence on knowledge of condition	Not known from this research publication
FSI – influence on engagement with self-care	
Results	
Grade	low
Include or Exclude	Include
Comments	This is a descriptive paper which offer suggestions and which led to the design on an on line intervention by this group. Suggestion that on line moderators are important

Data Extraction Template

Title of Article	Improving health-related quality of life of patients with chronic heart failure: effects of relaxation therapy
Year of Publication	2009
Author(s)	Yu D, Lee D, and Woo J.
Journal Name	Journal of Advanced Nursing
Country of research	China (Hong Kong)
Volume/Issue	
Methodology	Quantitative – RCT.
Focus, aims or objectives	Aim: to examine the effects of a relaxation training programme on health-related quality of life (QoL) in Chinese heart failure patients.
Outcome measure(s)	Health related QoL
Methods	Ethical approval: granted from the appropriate institution. Recruitment: participants recruited from a tertiary hospital. Random allocation of participants to one of two groups: relaxation training programme (n=79) or attention-control intervention (n=79). The FSI was facilitated by a research nurse. The control group received an attention-control intervention to balance the effect of the extra attention paid to the intervention group. Data collection: data collected at hospital discharge then after 8 and 14 weeks. Demographics data collected from participants' medical records. The research nurses who collected the data were blinded to the group status of the participants. Data analysis: the integrity of the randomisation was tested using independent t-tests and chi-square. Study data were subject to repeated measure analysis of variance and co-variance tests.
Sample strategy/size	Power calculation used to determine sample size. A total of 158 participants was the goal for the sample. 500 heart failure patients consecutively admitted to the hospital where the study was conducted were screened for eligibility to participate in the study. Of those 158 were recruited. 235 were ineligible, 18 died, 59 refused to participate and 30 were discharged before recruitment.

	Of the 158 recruited n=121 completed the study
Validated evaluation measures	World Health organisation QoL questionnaire
Formalised Social Intervention(FSI)	Relaxation training programme consisting of 2 x relaxation training sessions, 1 x skill revision workshop, twice daily relaxation self-practice and biweekly telephone follow up. This was facilitated by a research nurse.
Cause(s) of Loneliness	Not known from the research publication.
Patient needs if lonely	Not known from the research publication.
Impact of FSI on health outcomes	Not known from the research publication.
Impact of FSI on function outcomes	The FSI improved the participants’ emotional and social health related QoL at the first time point (8 weeks). No statistical difference was detected at the last data collection point (14 weeks) but a trend was noted that the intervention group had better emotional and social health related QoL compared with the control group..
FSI – influence on knowledge of condition	Not known from the research publication.
FSI – influence on engagement with self-care	Not known from the research publication.
Results	Participants in the intervention group had a statistically significant greater improvement in their psychological health related QoL 8 weeks after discharge from hospital.
Grade	High
Include or Exclude	Include
Comments	The details or the randomisation process and FSI have been reported elsewhere and so the information regarding this in the publication is minimal. The baseline data from the intervention group showed significantly better social support and so repeated measure analysis of variance was used to adjust for the initial difference. The improvement in health related QoL may be skewed since the initial baseline data were collected while the participants were hospitalised and the improvement could be attributed to general improvements in the participants’ heart failure exacerbation and recovery thereafter.