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Patients' experiences of cardiovascular health education and risk communication: a qualitative synthesis

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Abstract

Coronary heart disease (CHD) has no cure and patients with myocardial infarction are at high risk for further cardiac events. Health education is a key driver for patients' understanding and motivation for lifestyle change, but little is known about patients' experience of such education. In this review, we aimed to explore how patients with CHD experience health education and in particular risk communication. A total of 2221 articles were identified through a systematic search in five databases. 40 articles were included and synthesized by using thematic analysis. Findings show that both 'what' was communicated, and 'the way' it was communicated, had the potential to influence patients' engagement with lifestyle changes. Communication about the potential of lifestyle change to reduce future risk were largely missing causing uncertainty, anxiety and for some disengagement with lifestyle change. Recommendations for ways to improve health education and risk communication are discussed to inform international practice.

Introduction

Cardiovascular disease (CVD) is the leading cause of death globally (World Health Organisation, 2017) and coronary heart disease (CHD) is the most common manifestation of CVD. Patients with established CHD and a history of acute myocardial infarction (AMI) are at high risk for further cardiac events (Piepoli et al., 2016) with one in five patients suffering a second cardiovascular event within one year after an AMI (Jernberg et al., 2015). Therefore, educational interventions designed to change lifestyle behaviors as part of secondary prevention are key in reducing future cardiovascular events. Guidelines recommend that patients receive individualized advice and health education from health care professionals to support a healthier lifestyle and optimize heart health (Amsterdam et al., 2014; Fihn et al., 2012; Piepoli et al., 2016). However, a large scale survey across 27 countries indicates that success with healthy lifestyle change following AMI is rather limited (Kotseva et al., 2019).

An integral part of patient education is risk communication, which has been defined as “interactions and exchanges among individuals, groups, and institutions in the process of determining, analyzing, and managing risk” (Cho, Reimer, & McComas, 2015, p. 1). Communication about future cardiac risk should aim to enable patients to make informed decisions about the way they manage their heart health. This process is influenced by several factors including health literacy, information processing and interpretation, and the way information is delivered by health care professionals (Vahabi, 2007). An individual's perception of their personal risk for AMI is known to be a motivating factor for engaging in secondary prevention (Goulding, Furze, & Birks, 2010).

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3 The experience of health education and the processing of health information,
4 including perceived risk, is a dual process taking place on both emotional and
5 cognitive levels. Patients' experiences of communication about their own risk of
6 disease progression can have a significant impact leading to several emotional and
7 affective reactions (Dickert, Västfjäll, Mauro, & Slovic, 2015). Patients, and those
8 close to them, experience considerable levels of fear and anxiety about their future
9 and the risk of AMI recurrence (Astin, Horrocks, & Closs, 2014; Condon & McCarthy,
10 2006). However, the lack of success in secondary prevention suggests that patients
11 may not be fully aware of their own coronary risk factors and the potential for lifestyle
12 change to improve their heart health (Darr, Astin, & Atkin, 2008; French, Senior,
13 Weinman, & Marteau, 2001).

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29 The education that cardiac patients receive from health professionals whilst in
30 hospital, and beyond, is known to influence understanding and motivation to make
31 lifestyle changes. However, little is known about this process. Patients' personal
32 views and the perceived impact of recommended treatments on their quality of life
33 influence their decision making; but patients' views do not necessarily match those of
34 health professionals (Lewis, Robinson, & Wilkinson, 2003). To capitalize on the
35 beneficial effects of secondary prevention education we need to understand the
36 patients' perspectives. Although education alone does always not drive behavior
37 change (Kelly & Barker, 2016), there is evidence that it can improve health-related
38 quality of life and reduce future cardiovascular events (Anderson et al., 2017).

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Previous reviews of qualitative studies in the population of CHD and AMI have
focused on self-management of lifestyle changes and interventions pertaining to risk
reduction (Astin et al., 2014; Cohen & Kataoka-Yahiro, 2009; Guo & Harris, 2016;
Murray et al., 2013; Murray, Honey, Hill, Craigs, & House, 2012), or aspects such as

women's perceptions of heart disease (Hart, 2005), or perceived learning needs after coronary intervention (Gentz, 2000).

In this study, we aim to gain a better understanding of how people with coronary heart disease experience health education and in particular risk communication. The following question guided the review: How do patients with coronary heart disease experience health education and risk communication?

Methods

Design

Thematic synthesis (Thomas & Harden, 2008) was the chosen approach for this review. Thematic synthesis is a well-established method for qualitative systematic reviews which can be used to bring together the findings of individual studies, providing practitioners and researchers with an overview of a substantive body of qualitative studies which would otherwise be difficult to locate and interpret. Although we sought to develop themes that "went beyond" the concepts identified in the individual primary studies, we also endeavored to ground the themes within the evidence from these studies.

Search strategy

A systematic search was applied across five key databases (the Cochrane Library; CINAHL; MEDLINE; PsycINFO; SSCI) for studies published between January 1996 and November 2016. The search was updated by July 2018 in the databases MEDLINE and CINAHL, because these are two of the most relevant databases to find qualitative research (DeJean, Giacomini, Simeonov, & Smith, 2016).

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3 To optimize the search strategy and choice of databases we combined the
4 knowledge from different methodological articles (Booth, 2016; DeJean et al., 2016;
5 Flemming & Briggs, 2007; Shaw et al., 2004). The search was pre-planned and
6 tested to find an effective search strategy for each database. The search terms were
7 structured according to the SPIDER scheme (see supplementary Table 1) (Cooke,
8 Smith, & Booth, 2012). Search terms were adapted for each database (see example
9 in supplementary Table 2).

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20 Inclusion criteria were; studies in English or German with qualitative design or the
21 qualitative part of mixed methods studies, patients with established CHD and a
22 history of ST-elevation myocardial infarction (STEMI), non-ST-elevation myocardial
23 infarction (NSTEMI), acute coronary syndrome (ACS) and other related cardiac
24 events and percutaneous coronary interventions (PCI). Additionally, studies were
25 required to report at least one concept, metaphor or theme specifically about risk
26 communication or health education. Limitations according to the setting were not
27 defined. The search was limited to papers published after 1996 due to marked
28 changes in the characteristics of treatments for patients with coronary heart disease
29 and myocardial infarction (Nabel & Braunwald, 2012).

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44 The search results were imported into Covidence systematic review software
45 (Veritas, 2016) for sifting. Two investigators (Stefanie Mentrup and Timothy
46 Gomersall) independently screened articles for relevance at both the abstract and
47 full-text stage. Disagreements were resolved by discussion in the group of
48 researchers until consensus was reached. The results of the search are displayed
49 the Prisma Flow diagram (see supplementary Figure 1). The completed Enhancing
50 Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) (see
51 supplementary Table 3) provides details of the search strategy and review process
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3 (Tong, Flemming, McInnes, Oliver, & Craig, 2012).
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5 **Quality Appraisal**

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8 Study quality was independently evaluated by Stefanie Mentrup and Sascha Köpke
9 using the Critical Appraisal Skills Programme (CASP) criteria for qualitative research
10 (Critical Appraisal Skills Programme, 2018). Disagreements were discussed until
11 consensus was reached. The exclusion of studies in meta-syntheses on the grounds
12 of quality is a matter of ongoing debate (Carroll, Booth, & Lloyd-Jones, 2012;
13 Malpass et al., 2009). We decided not to exclude studies according to quality but
14 rather use the quality appraisal to inform our synthesis in terms of possible
15 limitations in the body of literature as a whole. The results of the quality appraisal of
16 each study subdivided into the questions 3-10 of the CASP checklist are shown in
17 the supplementary Figure 2. The color green is equivalent to “Yes” in the CASP
18 checklist, yellow to “Can’t tell” and red to “No”.
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34 **Data extraction and synthesis**

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37 The characteristics of included studies were extracted and collated (see
38 supplementary Table 4). The PDF of each study was imported into NVivo Version 11
39 for retrieval and coding. Findings were then synthesized in a three-part process.
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41 First, we undertook open coding of the study findings on risk communication, noting
42 key themes, and staying as close to the data as possible. Second, this list of codes
43 identified in the first stage was examined for similarities and differences, with the aim
44 of developing “analytical themes” (Thomas & Harden, 2008) which encapsulated a
45 greater cross-section of the data. Finally, these themes were used to develop an
46 overarching picture describing cardiac patients’ experience of health education and
47 risk communication. Hence, our analysis process was ‘bottom-up’, and guided by the
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3 language and themes in the original studies – no pre-determined coding scheme
4 was used. Through this process, we were able to develop 1) ideas about what made
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8 for more, or less effective, health education and risk communication and 2) an
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10 understanding of how these discussions influence cardiac patients' perceptions of
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13 their future risk and subsequent engagement with lifestyle change.
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15 Three members of the team (Emma Harris, Timothy Gomersall and Felicity Astin)
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17 from different professional disciplines undertook independent coding and recorded
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19 memos. To ensure the codes were being used consistently, we held regular team
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21 meetings in which we discussed our understanding of the emerging themes, and
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23 critically examined the usefulness of the coded data for illustrating each theme.
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25 Additionally, regular memo-writing on Nvivo version 11 allowed us to maintain an
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27 audit trail of how we developed the concepts. The transparency of our reporting is
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29 enhanced by the completed reporting framework (Tong et al., 2012) shown in the
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33 supplementary Table 3.
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35 36 37 **Results**

38 39 40 **Study Characteristics**

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43 From the 2221 studies identified in the searches, 40 studies with a total sample of
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45 1325 participants met the inclusion criteria and were included in the synthesis (see
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47 supplementary Figure 1). Studies were conducted across 13 countries with 60% (n =
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49 24) conducted in the UK. Summary information on included studies is shown in
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52 supplementary Table 4.
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Findings

The synthesis led to 3 themes and 10 categories that comprise the synthesis (see supplementary Table 5). Details of synthesis findings and contribution of individual studies to themes and categories are shown in supplementary Table 6. The three overarching themes are; 1. Patients' experiences of communication and health education interactions with health professionals, 2. Patients' views and preferences for risk and secondary prevention information and education, Patients' perceptions about "cardiac" risk.

1. Patients' experiences of communication and health education interactions with health professionals

This theme comprises 5 categories which illustrate how the characteristics of patient participant-health professional interactions can influence cardiac patients' experiences and their response to lifestyle advice.

1.1 Patient participation in educational interactions

There was diversity across the studies in the level of participant involvement in health education interactions, which showed a clear a continuum from active involvement to relative passivity. Some participants were forthcoming in asking health professionals questions or actively seeking health-related information (Abramsohn et al., 2013; Astin, Closs, McLenachan, Hunter, & Priestley, 2008; Attebring, Herlitz, & Ekman, 2005; Cartledge, Feldman, Bray, Stub, & Finn, 2018; Chan & Lopez, 2014; Crane, 2001; Gambling, 2003; Hagberth, Sjoberg, & Ivarsson, 2008; Hansen & Nelson, 2011; Hanssen, Nordrehaug, & Hanestad, 2005; Jensen & Petersson, 2003; Kerr et al., 2010; King, Sanguins, McGregor, & LeBlanc, 2007; Kristofferzon, Lofmark, & Carlsson, 2007; Moore, Kimble, & Minick, 2010;

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3 Svavarsdottir, Sigurdardottir, & Steinsbekk, 2016; Wang, Thompson, Chair, & Twinn,
4 2008; White, Bissell, & Anderson, 2010; Wiles & Kinmonth, 2001; Woodard,
5 Hernandez, Lees, & Petersen, 2005; Wright, Wiles, & Moher, 2001; Yamada &
6 Holmes, 1998).

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13 At the other end of the continuum, participants who were more passive put more
14 trust in the information received from professionals or from written information.
15 These patients had no desire to question the advice they received (Jensen &
16 Petersson, 2003; Wang et al., 2008; White et al., 2010; Wiles & Kinmonth, 2001;
17 Woodard et al., 2005; Wright et al., 2001; Yamada & Holmes, 1998).

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25 *“... why sort of double check something that somebody tells you... whom you*
26 *trust... if your website or your answers would have been the same as ours well*
27 *that confirms it, but I didn't feel I was in need of confirmation. [79-year-old male,*
28 *basic Internet experience].” (Kerr et al., 2010)*

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35 These different levels of participation in health education interactions between
36 patient participants and health professional could be explained partly by cultural
37 factors. One study reported that people from some cultures have different
38 perspectives on the way interactions with health professionals should play out and
39 did not feel comfortable questioning physicians or other health care providers.

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47 *“I think I've mentioned that, the native women, they're very quiet, they're not as*
48 *talkative and they [the physicians] ask them questions and sometimes it's just...*
49 *you know, quiet...” (King et al., 2007)*

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55 The level of patient participation in health information interactions can be explained
56 by individual personality factors, the level of trust in the health professional and
57 cultural factors.
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1.2 Finding a common language

Participants in several studies reported that they wanted health information and lifestyle advice to be provided to them by health professionals in an easy to understand language (Astin et al., 2008; Chan & Lopez, 2014; Crane, 2001; Gambling, 2003; Hagberth et al., 2008; Murie, Ross, Lough, & Rich, 2006; Svavarsdottir et al., 2016; Woodard et al., 2005). One barrier to understanding health information for participants was the use of complex medical terms (Attebring et al., 2005; Doyle, Fitzsimons, McKeown, & McAloon, 2012; Woodard et al., 2005);

“I keep asking questions, he’s talking real fast in very technical terms like it was none of my business.” (Woodard et al., 2005)

The use of a “common” language was appreciated by patient participants and facilitated understanding (King, Thomlinson, Sanguins, & LeBlanc, 2006; Wright et al., 2001). The lack of an interpreter for patient participants who did not speak English as a first language was another important barrier (Askham et al., 2010; Webster, Thompson, & Mayou, 2002; Woodard et al., 2005).

“They speak English, we speak Gujarati; poor things, how can they explain? It’s not their fault they speak English. Nobody even told me I’d had a heart attack.”
(Webster et al., 2002)

Some participants felt that the nurse or pharmacist was a good source of information and had the time available to explain information in a lay language (Astin et al., 2008; Cartledge et al., 2018; Hagberth et al., 2008; King et al., 2007; King et al., 2006; Kristofferzon et al., 2007; Svavarsdottir et al., 2016; Wright et al., 2001; Yamada & Holmes, 1998), whereas other participants preferred information to be provided by a doctor (Abramsohn et al., 2013; Astin et al., 2008; Hagberth et al.,

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3 2008; King et al., 2007; Pryor, Page, Patsamanis, & Jolly, 2014; Svavarsdottir et al.,
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5 2016).

8 **1.3. Open dialogue**

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11 Participants wished for health information to be communicated by health
12 professionals in an open, honest and non-judgmental way (Astin et al., 2008).
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14 Positive examples of open and frank communication were reported in five studies.
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16 These interactions were either in private rooms with doctors (Treloar, 1997) or part of
17 educational sessions about how to cope with anxiety and stress after serious illness
18 (Hagberth et al., 2008), smoking cessation advice (Hansen & Nelson, 2011), how to
19 self-manage lifestyle changes, (Kristofferzon et al., 2007) resumption of sexual
20 activity (Simony, Dreyer, Pedersen, & Birkelund, 2015). The educational sessions
21 took place in primary care, clinic and cardiac rehabilitation settings with nurses and
22 general practitioners. During these interactions health professionals were said to be
23 honest, professional, straight to the point, caring and spoke firmly in an easy to
24 understand way. These were the characteristics communications that patient
25 participants valued. In one study a participant explained that trust was developed
26 when a health professional was honest and admitted when they were uncertain
27 about the answer to a question;
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46 *“What is important in all this is that they just say that they don’t know. Because,*
47 *they don’t know. [...] Then, you start trusting them.”* (Svavarsdottir et al., 2016)
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51 Participants were also aware of the amount of time health professionals had
52 available to talk to them (Kerr et al., 2010). They often reported that nurses’ had a
53 main role in health education (Cartledge et al., 2018) or had more time to talk and
54 answer questions compared to doctors working in hospital settings (Hagberth et al.,
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3 2008; Kristofferzon et al., 2007; Simony et al., 2015). A communication style that
4 was perceived to be part of an 'open dialogue' led participants to report that they felt
5 satisfied with their care, more confident, knowledgeable and supported. Moreover,
6 levels of concern and worry were reduced and participants reported feeling more
7 receptive to adopting healthier behaviors (Hagberth et al., 2008; Hansen & Nelson,
8 2011; Kristofferzon et al., 2007; Simony et al., 2015). These examples show the
9 importance of communication and the characteristics of interactions which have the
10 potential to positively influence patients psychological and physiological health
11 outcomes.
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24 Conversely there were also examples of care episodes where opportunities for an
25 'open dialogue' about symptoms, exercise, sexual activity, medication adherence,
26 AMI diagnosis, heart disease and risk reduction, and health status were missed
27 (Abramsohn et al., 2013; Askham et al., 2010; Attebring et al., 2005; Crane, 2001;
28 Hagberth et al., 2008; Moore et al., 2010; Mosack & Steinke, 2009; Murie et al.,
29 2006; Smith, Frazer, Hall, Hyde, & O'Connor, 2017; Svavarsdottir et al., 2016). What
30 was perceived by patient participants as a "closed" communication style tended to
31 have a negative impact on secondary prevention behavior as participants reported
32 feeling less able to judge own abilities, less likely to exercise due to fear of
33 recurrence, more likely to forget to take medication and use a strategy of "trial and
34 error" to find out what they were able to do (Askham et al., 2010; Mosack & Steinke,
35 2009). Some participants reported a loss of trust in their educators and wanted to
36 change their doctor. Others were more assertive and "cornered" doctors to ask
37 specific questions to address topics they felt had been missed (Crane, 2001).
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57 Participants reported several barriers to an 'open dialogue' including lack of time, a
58 poor doctor-patient relationship and gender or socioeconomic inequality (Abramsohn
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3 et al., 2013; Crane, 2001; Kerr et al., 2010; Moore et al., 2010; Rompell, Gunold,
4 Schubmann, Richter, & Grande, 2013). In one study patient participants felt that their
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6 low socioeconomic status would unfavorably influence the level of care they
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8 received.
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13 Some female participants reported being aware of a power differential between them
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15 and male doctors which led them to feel that they were treated differently based on
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17 their gender (Moore et al., 2010).
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21 *“...It’s like they take a man that has a heart condition more seriously than they do*
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23 *a woman ... It just makes you feel like they don’t take you seriously. It just made*
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25 *me wonder why he didn’t talk to me like that ... He just didn’t seem to have the*
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27 *same care for me that he’d given the other patient ... I thought, maybe he has a*
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29 *problem with me, or maybe it’s because I’m a woman.”* (Moore et al., 2010)
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33 Female participants also reported that male doctors were reluctant to discuss
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35 resumption of sexual activity which was something some of them had wanted to talk
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37 about (Abramsohn et al., 2013).
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39 40 **1.4 Conflicting and confusing risk communication**

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43 The majority of studies described occasions where conflict or confusion arose during
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45 or following discussions about prevention and modification of coronary risk factors.
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47 Several participants described the information received about lifestyle changes to
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49 reduce coronary risk as confusing, which could cause anxiety and/or resulted in non-
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51 adherence to the recommended diet or exercise regime (Abramsohn et al., 2013;
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53 Attebring et al., 2005; Crane, 2001; Doyle et al., 2012; Gambling, 2003; Goldsmith,
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55 Lindholm, & Bute, 2006; Gulanick, Bliley, Perino, & Keough, 1998; Wang et al.,
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57 2008; Woodard et al., 2005).
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3 There were several factors that appeared to be associated with patient participants
4 feeling confused about their heart health and what they could safely. Key among
5 these were low health literacy levels and a lack of knowledge. Other factors were
6 feeling overwhelmed during hospitalization, prior misconceptions about AMI,
7 receiving conflicting or ambiguous information from different health professionals or
8 other information resources, or being given general rather than individualized
9 information (Abramsohn et al., 2013; Attebring et al., 2005; Crane, 2001; Doyle et al.,
10 2012; Gambling, 2003; Hanssen et al., 2005; Kristofferzon et al., 2007; Mosack &
11 Steinke, 2009; Romppel et al., 2013; Smith et al., 2017; Wang et al., 2008; White et
12 al., 2010; Wiles, 1998; Wiles & Kinmonth, 2001; Woodard et al., 2005).

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27 *“Before discharge, one doctor told me that it would be better for me to do some*
28 *exercise as early as possible. But when I saw another doctor, he said that it would*
29 *be better for me to take more rest and not do too much exercise... (Wang et al.,*
30 *2008)*

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37 In some instances conflict occurred when health professionals or family members
38 were perceived to be “fussing”, being insensitive or “lecturing” participants about
39 symptoms and lifestyle changes (Cartledge et al., 2018; Goldsmith et al., 2006;
40 Hansen & Nelson, 2011; Jensen & Petersson, 2003; Murie et al., 2006; Ruston &
41 Clayton, 2002; Woodard et al., 2005; Yamada & Holmes, 1998). This was most often
42 reported concerning smoking cessation and could lead to different outcomes;

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51 *“... it’s nearly caused me a couple of arguments to be quite honest, and I mean*
52 *proper arguments because I don’t like people telling me what to do.” (Hansen &*
53 *Nelson, 2011)*

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3 In some instances, the participant appeared to be more inclined to ignore the
4 information received whilst others felt more determined to change their health
5 behaviour. For some participants, conflict was more like an internal struggle.
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11 *“It’s like a tug-of-war with yourself...It’s like the devil and the good person.”*

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13 (Everett et al., 2011)
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16 The conflict played out internally between knowing what they should do to reduce
17 coronary risk and what they actually did in their daily life which often contradicted
18 recommendations (Dullaghan et al., 2014; Everett, DiGiacomo, Rolley, Salamonson,
19 & Davidson, 2011; Gambling, 2003).
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26 **1.5 Empathic interactions**

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28 Participants across some studies experienced, or expressed their need, for empathy,
29 encouragement and support from health professionals, cardiac rehabilitation
30 personnel, family or peer-support groups (Askham et al., 2010; Hansen & Nelson,
31 2011; Hanssen et al., 2005; Jensen & Petersson, 2003; Kristofferzon et al., 2007;
32 McSweeney & Crane, 2001; Simony et al., 2015; Smith et al., 2017; Svavarsdottir et
33 al., 2016; Treloar, 1997; White et al., 2010; Woodard et al., 2005; Wright et al., 2001;
34 Yamada & Holmes, 1998). Patient participants valued empathy from health
35 professionals in two ways. First they perceived it as beneficial in encouraging their
36 engagement with lifestyle change to reduce coronary risk. Secondly they viewed it as
37 an important factor to help them make a positive recovery. An empathic approach
38 from health professionals combined with the provision of support helped to build a
39 strong professional-patient relationship which in turn increased patients’ receptivity to
40 lifestyle changes (Hansen & Nelson, 2011; Kristofferzon et al., 2007; Simony et al.,
41 2015; Treloar, 1997; White et al., 2010; Woodard et al., 2005; Wright et al., 2001;
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3 Yamada & Holmes, 1998). Patient participants described a variety of ways in which
4 empathy was communicated to them during health education and risk
5 communication interactions. Verbal and non-verbal communication and active
6 listening were all identified as being an important part of positive consultations.
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13 *“She listens and smiles and talks to me about how I feel. She helps me with my*
14 *concrete matters. It is really nice seeing her, and I am always looking forward to*
15 *the next consultation.”* (Simony et al., 2015)
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20 Patient participants described the positive aspects of consultations in which health
21 professionals communicated that they understood the patient’s perspective and why
22 they might behave in a particular way. The provision of individualized support and
23 reassurance, active listening, positive facial expressions (smiling) and physical
24 contact (e.g. patting hand) were all aspects of the consultation that were appreciated
25 and valued. The tone and pace of the interaction was important as patient
26 participants wanted to feel that health professionals were genuinely interested and
27 that the discussion was not rushed (Kristofferzon et al., 2007).
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39 **2. Patients’ views and preferences for risk and secondary prevention**

40 **information and education**

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44 This theme describes cardiac patients’ experiences, views and preferences about
45 the health education process.
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49 **2.1 Modality, Timing and Amount of information and education**

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52 Participants’ preferences for health education and risk communication varied
53 considerably. Some participants preferred to receive health education and
54 information whilst in hospital, whereas others did not (Abramsohn et al., 2013;
55 Askham et al., 2010; Astin et al., 2008; Attebring et al., 2005; Gambling, 2003;
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3 Hanssen et al., 2005; McSweeney & Crane, 2001; Murie et al., 2006; Pryor et al.,
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5 2014; Svavarsdottir et al., 2016; Yamada & Holmes, 1998). Some participants were
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7 more likely to follow healthy lifestyle advice during recovery when they were more
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9 self-aware (Everett et al., 2011). This highlights the importance of individualizing this
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11 aspect of care. The timing of health education and the amount of information to be
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13 shared were closely linked; this meant that a 'balance' was required to avoid
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15 providing too much information at a time when it could not be absorbed. In one
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17 study, several patient participants explained that information on exercise and sexual
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19 intercourse were given too soon in the hospital post-AMI.
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24 *"I had information that was going to help in 12 weeks' time ... and I'm just lying*
25
26 *there thinking I'm going to have another heart attack."* (Murie et al., 2006)
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30 This contrasted with some participants reporting that they had received no
31
32 information or wanted more information on certain topics such as medications
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34 (Askham et al., 2010; Treloar, 1997) and the resumption of sexual activity
35
36 (Abramsohn et al., 2013). Participants preferred health education that was
37
38 individualized, communicated using lay terms and images, delivered face-to-face
39
40 using discussion rather than a didactic teaching approach (Astin et al., 2008; Kerr et
41
42 al., 2010; Rompell et al., 2013; Simony et al., 2015; Svavarsdottir et al., 2016;
43
44 Wright et al., 2001). Participants' perceived need for information appeared to
45
46 decrease with time since diagnosis meaning that health education should be 'front
47
48 loaded' to provision during early stages of recovery (Kerr et al., 2010).
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52 Information on secondary prevention activities was communicated using a variety of
53
54 different modalities. Verbal information was communicated by health professionals,
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56 family and friends and supplemented by audio-visual aids, angiogram images,
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58 anatomical heart models, information leaflets, internet based education, and
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3 graphical descriptions (Askham et al., 2010; Astin et al., 2008; Chan & Lopez, 2014;
4 Crane, 2001; Gambling, 2003; Gulanick et al., 1998; Hanssen et al., 2005; Jensen &
5 Petersson, 2003; Kerr et al., 2010; King et al., 2007; King et al., 2006; Kristofferzon
6 et al., 2007; Mosack & Steinke, 2009; Murie et al., 2006; Wiles, 1998; Wiles &
7 Kinmonth, 2001; Yamada & Holmes, 1998). Written information was considered to
8 be less useful than other methods whilst participants were in-patients, mainly
9 because they were often too exhausted to read or the content was not sufficiently
10 detailed or individualized (Askham et al., 2010; Chan & Lopez, 2014; Gambling,
11 2003).

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25 *“The whole days I was there is kind of a mixed -up sort of thing. It is like a dream.*

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27 *I am not quite sure I could pinpoint everything that happened...”* (Yamada &
28 Holmes, 1998)

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Written information was considered more useful when it was provided, or read, after
hospital discharge to aid recall of verbal information (Astin et al., 2008; Romppel et
al., 2013). However, some participants found it difficult to understand the information
leaflets because the language was too complex (King et al., 2007) and others did not
read them at all (Webster et al., 2002). Participants' responses to internet and media
sources were mixed with information viewed as useful, confusing or untrustworthy
(Chan & Lopez, 2014; Crane, 2001; Gulanick et al., 1998; King et al., 2006).
Participants from several studies valued cardiac rehabilitation supplemented with
written booklets and videos as a source of information and support from their peers,
nurses, heart specialists and physiotherapists (Hanssen et al., 2005; King et al.,
2006; McSweeney & Crane, 2001; Mosack & Steinke, 2009; Pryor et al., 2014;
Romppel et al., 2013; Smith et al., 2017; Wiles & Kinmonth, 2001; Yamada &
Holmes, 1998).

2.2 Generic information

Many patient participants across studies experienced a lack of individualized health education. This meant that they were uncertain about what secondary prevention activities would be the most beneficial to them and were uncertain about future cardiac risk. The information provided by health professionals was described as stereotypical, generalized and not specific to their condition or situation;

“All the women reported receiving verbal health information from their HCP. However, most of the verbal information provided was vague and nonspecific such as ‘lose weight,’ ‘start exercising,’ ‘eat right,’ and ‘don’t overdo’.” (Crane, 2001).

In particular, vague information was provided for resumption of sexual activity (Abramsohn et al., 2013; Wang et al., 2008), discharge information (Askham et al., 2010), tobacco smoking cessation (Askham et al., 2010; Crane, 2001; Hanssen et al., 2005), physical activity and exercise (Astin et al., 2008; Crane, 2001; Gambling, 2003; Wang et al., 2008), medication management (Attebring et al., 2005; Treloar, 1997; Wang et al., 2008), detail about AMI diagnosis (Crane, 2001; Gambling, 2003; Hanssen et al., 2005; Murie et al., 2006), dietary recommendations (Crane, 2001; Doyle et al., 2012; Gambling, 2003; Murie et al., 2006; Wang et al., 2008), prognosis (Gambling, 2003; Svavarsdottir et al., 2016; Wiles, 1998) and details about general lifestyle factors (Kristofferzon et al., 2007; Romppel et al., 2013; Svavarsdottir et al., 2016; Wiles, 1998).

In addition to verbal communication, information booklets, web-based interventions and cardiac rehabilitation programs were described as providing generalized information in relation to AMI diagnosis, prognosis and lifestyle factors (Gambling,

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2
3 2003; Hanssen et al., 2005; Kerr et al., 2010; Svavarsdottir et al., 2016; White et al.,
4
5 2010). This was identified as a significant barrier to implementing behavior/lifestyle
6
7 change to reduce coronary risk. The lack of detailed and individualized information
8
9 led to a range of negative mood states such as anxiety (Astin et al., 2008; Gambling,
10
11 2003), dissatisfaction (Hanssen et al., 2005) and a loss of trust in health
12
13 professionals (Svavarsdottir et al., 2016). This led to some participants (Crane, 2001;
14
15 Wiles, 1998) becoming unreceptive to lifestyle guidance and recommendations
16
17 (Hanssen et al., 2005; Svavarsdottir et al., 2016).
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20

21
22 There were also several examples of good practice (Yamada & Holmes, 1998). One
23
24 powerful example of individualization was the provision of participants' before and
25
26 after angiogram image, which acted as a "source of reassurance" and a "reminder to
27
28 not smoke cigarettes" (Astin et al., 2008). Provision of individualized and specific
29
30 information increased participants' trust in health professionals and led to them
31
32 feeling more prepared for life after discharge home (Hanssen et al., 2005;
33
34 Svavarsdottir et al., 2016). This type of information also influenced participants to
35
36 continue with cardiac rehabilitation and changed attitudes about engaging in self-
37
38 care (McSweeney & Crane, 2001; Simony et al., 2015).
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43 **2.3 Missing information**

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46 Across studies there were frequent reports of participants not receiving information
47
48 about secondary prevention information and risk communication within health
49
50 education interactions.
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54 Participants' accounts rarely included any recollection of clear information, verbal or
55
56 numerical information, about the degree of damage to the heart muscle and any
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3 estimate of the future risk of a second AMI. This may be because participants were
4 not given this information, did not remember it or chose not to mention it.
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8 Many participants stated that specific information was not provided by health
9 professionals during hospitalization, but five studies also reported missing
10 information in support classes, written leaflets, at home and on the internet
11 (Abramsohn et al., 2013; Astin et al., 2008; Chan & Lopez, 2014; Hanssen et al.,
12 2005; Webster et al., 2002). Topics that were lacking included advice on dietary
13 change, medication (purpose and side effects), tobacco smoking cessation advice
14 and counseling, resumption of sexual activity, physical exercise, prognosis, AMI
15 diagnosis, how to interpret signs and symptoms indicating a need to seek medical
16 advice, coping with comorbidities, CHD disease process and coronary risk factors,
17 recovery expectations and timescales and details of any future treatments that may
18 be required (Abramsohn et al., 2013; Askham et al., 2010; Astin et al., 2008;
19 Attebring et al., 2005; Cartledge et al., 2018; Chan & Lopez, 2014; Crane, 2001;
20 Doyle et al., 2012; Gambling, 2003; Gulanick et al., 1998; Hagberth et al., 2008;
21 Hansen & Nelson, 2011; Hanssen et al., 2005; Jensen & Petersson, 2003;
22 Kristofferzon et al., 2007; Mosack & Steinke, 2009; Smith et al., 2017; Wang et al.,
23 2008; Webster et al., 2002; Wiles, 1998; Wright et al., 2001; Yamada & Holmes,
24 1998).
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48 *“[I]t should be something that the doctors do talk to women about ... when they’ve*
49 *had a heart attack... [S]ex is strenuous and it’s a lot on your heart muscles...*
50 *They tell you when you have a heart attack not to run the vacuum cleaner, not to*
51 *do this or that for so many months after... Why not say, as far as your sexual*
52 *activity, hold off for 4 weeks until you come back?”* (Abramsohn et al., 2013)
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3 Six studies reported that some participants were unaware of cardiac rehabilitation
4 programmes (Gulanick et al., 1998; Jensen & Petersson, 2003; Kristofferzon et al.,
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6 2007; McSweeney & Crane, 2001; Smith et al., 2017; Webster et al., 2002) and two
7
8 studies reported missing information on the implications of CHD diagnosis for
9
10 returning to work (Attebring et al., 2005; Hanssen et al., 2005).
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15 In some instances, it was unclear as to whether important health information had
16
17 been provided as part of on-going health education.
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21 *“I feel that I have not yet really talked with any doctor that has described more*
22
23 *precisely where my infarction is located, what I shall do in my life and what is*
24
25 *suitable for me. I need to discuss these things with somebody.”* (Attebring et al.,
26
27 2005).
28
29

30 This may have been because detailed information had been missed or because
31
32 participants could not recall it due to being emotionally overwhelmed following their
33
34 diagnosis (Abramsohn et al., 2013; Askham et al., 2010; Astin et al., 2008; Attebring
35
36 et al., 2005; Gambling, 2003; Hagberth et al., 2008; McSweeney & Crane, 2001;
37
38 Webster et al., 2002). Generally, a lack of detailed information, especially on
39
40 secondary prevention and lifestyle changes, acted as a barrier to patients being able
41
42 to fully engage with, and adopt, healthy lifestyle behaviors. This situation was
43
44 frequently worsened when participants misunderstood health information about their
45
46 future coronary risk. (Gambling, 2003; Hansen & Nelson, 2011; Smith et al., 2017;
47
48 Wiles, 1998).
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53 **3. Patients' perceptions about 'cardiac' risk**

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56 This theme illustrates patients' perceptions of their future 'cardiac risk', i.e. subjective
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58 views on individual risk of a future AMI and their interpretation of factors that would
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3 potentially increase or decrease their perceived risk. Participants' experiences of
4 health education and risk communication were a significant factor in shaping their
5 perception of their 'cardiac risk' and influenced their engagement with lifestyle
6 change.
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13 **3.1 Fear of myocardial infarction recurrence**

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16 An important finding was the lack of information about future risk which was 'missing'
17 from participants' accounts described in section 2.3. This meant that patients
18 participants were left to 'fill the gaps' meaning that their individual interpretations of
19 the health 'talk' were amalgamated with their lay knowledge about their diagnosis
20 and prognosis. Many participants voiced concern about their prognosis and risk of
21 having another myocardial infarction (Astin et al., 2008; Attebring et al., 2005;
22 Gambling, 2003; Gulanick et al., 1998; Hagberth et al., 2008; Hanssen et al., 2005;
23 Jensen & Petersson, 2003; Smith et al., 2017; Treloar, 1997; Wiles, 1998). This led
24 to fear and anxiety which were common emotions amongst participants that could
25 either motivate, or demotivate them, to make healthy lifestyle changes. For example,
26 the fear of dying or having another cardiac event motivated some participants to eat
27 more healthily (Doyle et al., 2012), abstain from alcohol (Chan & Lopez, 2014), start
28 exercising (King et al., 2006; Moore et al., 2010) or stop smoking (Dullaghan et al.,
29 2014; Gambling, 2003).
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49 *"I just want to stay healthy, you know. I just don't want to be in hospital again. I*
50 *don't want them to have to put another stent in or need bypass surgery. I just don't*
51 *want to be in hospital again, so that is the main reason to stay healthy. I want to*
52 *stay alive for a wee bit longer."* (Doyle et al., 2012).
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3 Other participants were fearful of resuming exercise, sexual activity or activities of
4 daily living (Abramsohn et al., 2013; Askham et al., 2010; Astin et al., 2008; Attebring
5 et al., 2005; Gambling, 2003; Goldsmith et al., 2006; Hanssen et al., 2005;
6 Kristofferzon et al., 2007; Mosack & Steinke, 2009; Smith et al., 2017; Wang et al.,
7 2008; White et al., 2010; Woodard et al., 2005) until they had received further advice
8 from health professionals at cardiac rehabilitation or at their next outpatient
9 appointment.

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20 Fear of damaging their heart further was frequently mentioned as a possible risk
21 associated with exercise (Askham et al., 2010; Astin et al., 2008; Attebring et al.,
22 2005; Gambling, 2003; Hanssen et al., 2005; Kristofferzon et al., 2007; Smith et al.,
23 2017; Wang et al., 2008; Webster et al., 2002). There was also some uncertainty
24 about the most important dietary changes to make post AMI (Askham et al., 2010;
25 Chan & Lopez, 2014).

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34 *“I heard from the radio saying that eating tomato is good for the heart. I do not*
35 *know whether it is true or not...It is not easy [to ask others for information].”* (Chan
36 & Lopez, 2014).

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42 Some participants did not always make the link between a lifestyle choice and the
43 risk of AMI recurrence (Moore et al., 2010; Svavarsdottir et al., 2016; Wang et al.,
44 2008). Others tended to be selective about the coronary risk factors they paid most
45 attention to whilst dismissing others. This appeared to be a coping process that
46 seemed to enable them to ‘sit’ more comfortably with their diagnosis (Askham et al.,
47 2010; Ruston & Clayton, 2002). Others talked rather reluctantly about a new set of
48 ‘rules’ that now shaped their future lifestyle (Astin et al., 2008).

3.2 Feeling fixed and cured

The way participants interpreted the language and phrases used by health professionals to convey health messages to them was important. Participants often focused upon and retained specific phrases about their diagnosis which were communicated to them (e.g. “fixed”, ‘the ECG was clear’, ‘Your heart is good’). Sometimes these phrases were repeated by participants and used out of context, as either a source of reassurance, or as a means to justify a lifestyle choice (Dullaghan et al., 2014; Everett et al., 2011; Smith et al., 2017).

“... they said, ‘Your heart is good’ after the angiogram... I got a false sense of security... I am using it as an excuse not to rouse myself... to go out walking, the smoking... I am probably in denial...” (Smith et al., 2017)

The way in which health professionals communicated the extent, and severity of the AMI, as part of the health education process influenced patient participant responses to lifestyle advice and information. For example, when health professionals explained the seriousness and implications of the AMI bluntly, participants appeared to pay more attention to the advice compared to when health professionals used less confronting terms such as ‘fixed’ (Astin et al., 2008; Everett et al., 2011; Hansen & Nelson, 2011).

“She actually sat down and said you do realise, do you realise what you’ve been brought in for? And I says yeah I think so and she says well you’ve had a heart attack and she said it’s been a nasty, you know more of, saying it was quite a nasty one and that was important for me. If she’d just said well you’ve had a mild heart attack or you’ve had like a warning I’d have probably just been a bit oh thank God for that and probably a bit more (short pause) I don’t know if I would have

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3 *been, but I probably would have been a bit more, oh well yeah, I'll cut down on*
4 *this, I'll cut down on that, but because of the way she worded it and the way she*
5 *stated it, she made me sit up and think ooof it's, if you understand what I mean?"*
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10 (Astin et al., 2008).
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12 Many participants were initially motivated to adopt a healthier lifestyle immediately
13 post-discharge from hospital due to their belief that they would make a complete
14 recovery. However, the maintenance of lifestyle change was difficult for
15 asymptomatic patients (Wiles, 1998; Wiles & Kinmonth, 2001) as they lacked a
16 reminder of their disease which was invisible to them. Participants who perceived
17 their treatment as curative often had misplaced optimism which led to a reduced
18 motivation to engage in lifestyle changes (Doyle et al., 2012). On the other hand,
19 emphasizing the chronic and progressive nature of cardiovascular illness led to a
20 sense of futility among some participants (Gulanick et al., 1998; Hansen & Nelson,
21 2011).
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35 *"...You can't stop the process. The doctor told me my problem was all on the left*
36 *side of my heart. But he could not guarantee that the right side was going to stay*
37 *clear. So that's a nice prognosis-look forward to the right side clogging up!"*
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42 (Gulanick et al., 1998)
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45 These different accounts and perspectives demonstrate the delicate balance
46 between unrealistic optimistic or over pessimism; both have the potential to
47 negatively or positively impact upon engagement with healthy lifestyle change.
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Discussion

In this review, data from forty studies, conducted across thirteen countries, were synthesized to provide an in-depth account of how people diagnosed with CHD experience health education and risk communication. Three themes were the product of the final synthesis; 'Patients' experiences of communication and health education interactions with health professionals', 'Patients' views and preferences for risk and secondary prevention information and education' and 'Patients' perceptions about "cardiac" risk'. Notably, none of the studies identified in our systematic search focused specifically on experiences of risk communication among patients with CHD. Rather, risk communication was discussed as one component of clinical care – for example, in cardiac rehabilitation programs. This suggests that risk communication experiences among CHD patients should be an urgent research priority. Nevertheless, our systematic review provides an important contribution to this knowledge by synthesizing the disparate information about risk communication for the first time, and developing an integrated set of novel conceptual themes.

The perceived quality of patients' interactions with health professionals was affected by a complex and interacting array of linguistic, interpersonal, sociocultural, and emotional issues. To briefly summarize these: the use of complex medical jargon, rather than a 'common language' made it difficult for patients to fully understand the information being communicated to them. Patients' experiences of communication and health education interactions were influenced by the rapport that evolved with the health professional as well as the language and terminology used. An 'open-dialogue' which was perceived as honest, and non-judgmental, was important. Expressing uncertainty about a health outcome was not seen as negative, but as

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3 part and parcel of honest clinical communication. By contrast, there were several
4 instances in which participants received conflicting and confusing information.
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6 Empathic interactions were valued by patients. A rapport that conveyed empathy,
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8 communicated using either verbal or non-verbal techniques, made patients feel that
9
10 they were understood and cared for. Finally, patient demographics, health literacy
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12 levels and the perceived attitudes and gender of health professionals were powerful
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14 factors that influenced the level of patient engagement in healthcare.
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21 These findings represent a challenge for health professionals as the characteristics
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23 of the interaction are shaped by patient preferences, which vary both within, and
24
25 across, individuals. For example, some patients prefer a level of uncertainty as this
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27 approach can support hope and optimism in the face of adversity, whilst others find
28
29 uncertainty more of a threat and seek clarity (Brashers, 2001). Our findings about
30
31 conveying uncertainty differ from other studies, which have reported that expressing
32
33 uncertainty, particularly about prognosis, can erode the level of trust and belief that
34
35 patients have in clinicians' professional competency (Bhise et al., 2018). Empathy is
36
37 another highly complex issue: While being recognized as a key factor in human
38
39 relationships (Mercer & Reynolds, 2002), the definition and use of empathy in clinical
40
41 contexts has been a matter of longstanding concern and debate (Halpern, 2014).
42
43 Based on our review findings, it seems unwise to suggest there is any satisfactory
44
45 "correct" way to handle these issues in risk communication. Rather, we are
46
47 highlighting that a series of dilemmas faced by clinicians in any communication with
48
49 CHD patients, calling on a willingness to hear the patient narrative and to exercise
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51 "practical wisdom" (Charon, 2001; Hunter, 1996; Salmon & Young, 2011). For
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53 instance, empathy, while a valuable feature of communication, can be perceived as
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55 "inauthentic" if handled inappropriately (Salmon & Young, 2005). In terms of
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3 conveying uncertainty, patients are often coping with conflicting desires which
4 clinicians have to negotiate. In a survey of cancer patients, 100% of patients wanted
5 doctors to be honest communicators, yet 91% also wanted them to be optimistic
6 (Kutner, Steiner, Corbett, Jahnigen, & Barton, 1999). The conflict between the need
7 for patients 'to know' on the one hand, but 'not really wanting to know', was also
8 evident in findings from a survey of cardiac patients about their preferences for
9 coronary angioplasty risk information; 90% of participants agreed that they wanted to
10 be told about all of the procedural risks, yet 20% of the same participants also
11 agreed that they preferred to know nothing about the procedural risks (Astin et al.,
12 2019). From this we can conclude that 10% answered yes to both items, indicating
13 that they were experiencing dissonance in their preferences.
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30 This conflict in risk information preferences emphasizes the importance of
31 individualizing risk communication to reflect the differences in the way that people
32 perceive risk. Findings from the second theme highlighted patients' views and
33 preferences for health education on lifestyle change. Patients preferred verbal
34 information supplemented by written information. A key finding was the need to
35 'balance' the amount of health information and education with the 'timing' of
36 provision. A 'stepped approach' to secondary prevention health education and risk
37 communication appears to be preferred by patients so that the educational content
38 matches their preference and stage of recovery. Patients' learning preferences will
39 change over time. Timmins (2005) and Gentz (2000) reported that patients focused
40 upon survival and the management of symptoms during early recovery after AMI. It
41 is also important to avoid information overload during early recovery and to provide
42 regular contacts to support patient comprehension and recall. Ongoing
43 communication and education after hospital discharge and rehabilitation can have a
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3 positive effect on the patients' outcomes and self-management skills (Guo & Harris,
4 2016; Street, Makoul, Arora, & Epstein, 2009). A holistic approach to patient
5 education and communication supports shared decision-making and encourages the
6 active engagement of patients in their healthcare; all of which are central to patient-
7 centered care (Lusk & Fater, 2013; Scholl, Zill, Harter, & Dirmaier, 2014). Current
8 guidance on the provision of health education for patients with CHD recommends
9 that patients' learning needs should be considered and resources provided in plain
10 language using a variety of formats (Amsterdam et al., 2014; British Association for
11 Cardiovascular Prevention and Rehabilitation, 2017; Fihn et al., 2012; Piepoli et al.,
12 2016). It is not clear how involved patients have been in the development of current
13 guidance which may mean that their preferences are not fully considered.
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30 Another key finding in this synthesis was the consistent reporting among patients
31 that health education was not sufficiently individualized. More often than not, 'generic
32 information' was presented using didactic teaching approaches. The provision of
33 general information, rather than individualized information, was consistent across all
34 aspects lifestyle change recommendations. This is possibly because clinicians and
35 patients understand 'risk' in different ways; clinicians tend to see risk more
36 analytically and focus on clinical evidence, whereas patients understand risk in the
37 light of their own personal experience and the impact upon their own life situation
38 (Street et al., 2009). Individualizing risk information and advice is, undoubtedly,
39 another complex and dilemmatic issue for clinicians. On the one hand, the evidence
40 in this review clearly suggests that generic risk information is unhelpful. Yet tailoring
41 risk information to the individual is itself a risky business. Given the uncertainty of
42 clinical outcomes for every individual case, clinicians should avoid unwarranted
43 suggestions of outcome certainty. Some (Skelton & Greenyer, 2008) have gone so
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3 far as to suggest that communication outcomes are necessarily restricted to
4 generalizations. This notwithstanding, we suggest that clinical evidence and
5 evidence-based recommendations must be brought together with the unique
6 patient's values and circumstances to enable patients to make informed decisions
7 (Hoffmann, Montori, & Del Mar, 2014). This is important so that patients can prioritize
8 which lifestyle changes they make and recognize that this may reduce their risk of a
9 future cardiac event.
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21 The issue of individualization relates strongly to the third theme in this synthesis,
22 which focuses upon patients' perceptions of their personal 'cardiac' risk. Discussions
23 about the risk of recurrence, degree of damage to the heart, anticipated progression
24 of the disease and sudden death appeared to be avoided and remained unspoken.
25 This may be because such discussions are not reported in the research literature,
26 patients may have forgotten them, or the discussions may have never taken place.
27 However, at times, research participants were explicit in stating that topics of
28 importance to them were omitted from clinical communication. Such topics included
29 complex information, such as the extent of heart damage, or sensitive topics, notably
30 advice on sexual activity. Some patients were also unaware of the existence and
31 value cardiac disease prevention and rehabilitation programs which are education
32 and exercise based interventions designed to support recovery after hospital
33 discharge. One notable exception to the issue of insufficiently individualized
34 information was reported in Astin et al. (2008): The provision of patients' angiograms
35 demonstrated the extent of heart damage in a tangible way, which was said by some
36 participants to act as a motivation for lifestyle change. This represents a promising
37 avenue for further research to examine in detail.
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3 For many patients the fear of a second AMI had a major impact on their recovery
4 and in particular their willingness to resume activities linked to physical exertion.
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6 Patients' beliefs about the risk of AMI recurrence may have been inaccurate and if
7
8 overly pessimistic could contribute to depression and anxiety which is common
9
10 amongst cardiac patients (Huffman, Celano, Beach, Motiwala, & Januzzi, 2013), and
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12 which can hamper patients' capabilities for self-management. On the other hand,
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14 patients in some studies appeared to pay more attention to information which was
15
16 more positively framed in terms of healing and full recovery after AMI. The language
17
18 used by some patients in this body of research – that they were 'cured', or that the
19
20 treatment had 'fixed' their hearts – reflects a widespread misconception about AMI
21
22 recovery (Astin & Jones, 2006; Sampson, O'Cathain, & Goodacre, 2009).
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30 Framing effects have been studied extensively by psychologists and behavioral
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32 economists, and are likely to have an important impact on patients' experiences of
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34 risk communication. For example, patients are known to systematically over-estimate
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36 risks and benefits if they are presented in relative, rather than absolute terms
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38 (Malenka, Baron, Johansen, Wahrenberger, & Ross, 1993), and clinicians should be
39
40 careful to avoid instilling unnecessary anxiety on the one hand, or unwarranted
41
42 optimism on the other. Achieving a good understanding of risk among CHD patients
43
44 is a major challenge, requiring continued efforts to promote collective statistical
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46 literacy (Gigerenzer, Gaissmaier, Kurz-Milcke, Schwartz, & Woloshin, 2007).
47
48 However, such efforts will yield significant payoffs, by empowering CHD patients to
49
50 make informed decisions about their health. Interestingly, detailed discussions about
51
52 the potential of lifestyle change to reduce future AMI risk appeared to be largely
53
54 missing. This represents a lost opportunity. A clearer message about the potential of
55
56 healthy lifestyle change and medication adherence as a way to slow CHD disease
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3 may support patient self-efficacy. Low self-efficacy is a predictor for non-participation
4 in cardiac disease prevention and rehabilitation programs (Murray et al., 2012).
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9 There are limitations to this review, as there are with all reviews, and results should
10 be interpreted with these in mind. The search strategy designed for this review may
11 have omitted relevant studies. Qualitative studies are acknowledged as being difficult
12 to identify. In addition, the studies included in this review were often designed to
13 explore the general recovery experiences of AMI participants. A significant finding
14 was the lack of studies addressing the topic of risk communication in cardiac
15 settings.
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27 Findings show that both 'what' was communicated, and 'the way' it was
28 communicated, had the potential to influence patient's engagement with lifestyle
29 changes. Detailed discussions about the potential of lifestyle change to reduce future
30 cardiac risk were largely missing causing uncertainty, anxiety and for some
31 disengagement with lifestyle change.
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40 **Implications for practice**

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43 Findings from this synthesis of international research provide some key themes to
44 inform clinical practice. The individual characteristics of both the patient and health
45 professional provide the context for the patient experience of health education and
46 risk communication. Therefore, we recommend that health professionals be given
47 the opportunity to reflect on how they communicate with patients, and their families,
48 to provide support for recovery after a cardiac event. Health professionals will benefit
49 from skills training. Focus needs to be given to supporting health professionals to
50 individualize health-information, using plain language, on the topics that matter to
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3 patients. Some techniques used to broach difficult conversations about risk would be
4
5 a valuable addition to communication skills education in addition to the use of
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7 'Teach-back' to support patient comprehension. More attention is required to ensure
8
9 that educational content focuses upon topics that are currently 'missing' from heart
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11 health curricula. By adopting these approaches patients may have a more realistic
12
13 understanding of their cardiac risk combined with relevant information to enable
14
15 them to make lifestyle changes and manage their medications.
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20 21 **Implications for research**

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24 There is a need for research that focuses specifically upon experiences of health
25
26 education and risk communication in cardiac settings. Patients and those close to
27
28 them, need stronger representation in the professional groups that make decisions
29
30 about what topics are included in heart health curricula. Qualitative studies can
31
32 explore patients' views and preferences for risk communication. Quantitative studies
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34 can help us to understand which formats may be the most effective to communicate
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36 cardiac risk to patients in a way that they can understand. Discussions about
37
38 prognosis, recurrence and progression of the disease are a challenge for patients,
39
40 those close to them and health professionals. There may be lessons learnt about
41
42 broaching difficult conversations in cancer care settings (Fallowfield & Jenkins, 2004;
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44 Moore, Rivera, Bravo-Soto, Olivares, & Lawrie, 2018) that could be transferable into
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46 cardiac settings.
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52 53 54 **Conclusion**

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57 Health education and risk communication has the potential to influence patients'
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59 engagement and motivation to make healthy lifestyle changes to reduce future
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3 coronary risk. However, patients continue to report unmet health information needs
4 and detailed discussions about the potential of lifestyle change to reduce future risk
5
6 were largely missing causing uncertainty, anxiety and for some disengagement with
7
8 lifestyle change.
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22
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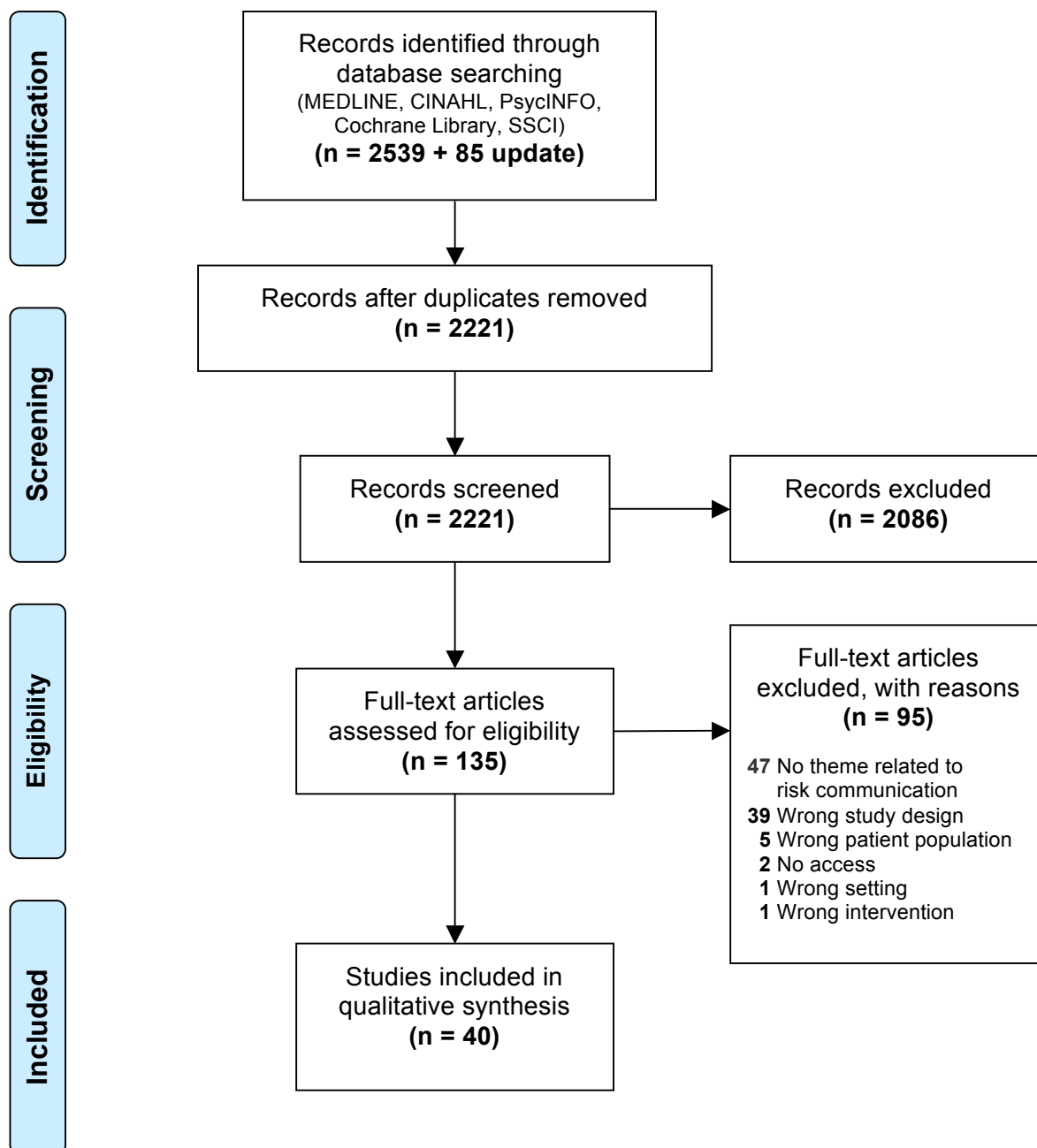
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Supplementary Figure 1

PRISMA Flow diagram of the literature search (Moher, Liberati, Tetzlaff, Altman, & The Prisma Group, 2009)

PRISMA Flow Diagram



Supplementary Figure 2 Quality appraisal CASP (Item 3-10)

	(3) Aims of Research	(4) Recruitment strategy	(5) Data collection	(6) Relationship	(7) Ethics	(8) Data analysis	(9) Findings	(10) Value
Abramsohn 2013	+	+	+	?	?	+	+	+
Askham 2010	+	?	+	?	+	+	+	+
Astin 2008	+	+	+	+	+	+	+	+
Attebring 2005	+	+	?	+	+	+	+	+
Cartledge 2018	+	+	+	+	+	+	+	+
Chan 2014	+	+	+	?	+	+	+	+
Crane 2001	+	+	+	+	+	?	?	+
Doyle 2012	+	+	?	+	+	+	+	+
Dullaghan 2014	+	+	+	?	+	+	+	+
Everett 2011	+	?	?	?	?	+	+	?
Gambling 2013	+	?	+	+	+	?	?	+
Goldsmith 2006	+	+	?	+	?	+	?	+
Gulanick 1998	+	+	+	+	+	+	+	+
Hagberth 2008	+	+	+	+	+	+	+	+
Hansen 2011	+	+	+	?	+	+	+	+
Hanssen 2005	+	+	+	+	+	+	?	+
Jensen 2003	+	+	+	+	+	+	+	+
Kerr 2010	+	?	+	+	?	?	+	+
King 2006	+	+	+	+	?	+	?	?
King 2007	+	+	+	+	+	+	+	?
Kristofferzon 2007	+	+	+	+	+	+	?	+
McSweeney 2001	?	+	+	+	?	+	+	+
Moore 2010	+	+	+	+	+	+	+	+
Mosack 2009	+	?	+	?	?	+	+	+
Murie 2006	+	+	?	+	?	?	?	+
Pryor 2014	+	+	+	?	?	+	+	+
Romppel 2013	+	+	+	+	?	?	?	+
Ruston 2002	+	?	+	+	+	+	+	?
Simony 2015	+	?	+	+	+	+	+	+
Smith 2017	+	+	?	+	?	+	+	+
Svavarsdottir 2016	+	+	+	?	+	+	+	+
Treloar 1997	+	+	+	+	+	+	+	?
Wang 2008	+	+	+	+	+	+	+	+
Webster 2002	+	+	+	+	+	+	+	+
White 2010	+	+	+	+	?	+	+	+
Wiles 1998	+	+	+	+	?	?	?	?
Wiles 2001	+	+	?	+	+	+	+	+
Woodard 2005	+	+	+	?	+	+	+	+
Wright 2001	+	+	+	+	+	+	+	+
Yamada 1998	+	+	+	+	+	+	+	+

Peer Review

Supplementary Table 1

Search terms and combination

SPIDER (Cooke et al., 2012)	Search terms*
S – Sample	myocardial infarction [MeSH] OR heart attack OR acute coronary syndrome [MeSH] OR coronary disease [MeSH] OR coronary heart disease OR coronary artery disease [MeSH] OR myocardial revascularization [MeSH] OR percutaneous coronary intervention [MeSH] OR angioplasty, balloon, coronary [MeSH] OR percutaneous transluminal coronary angioplasty OR fibrinolysis OR coronary artery bypass [MeSH] OR coronary artery bypass grafting
PI – Phenomenon of Interest	risk communication OR health communication [MeSH] OR risk perception OR risk interpretation OR risk framing OR risk literacy OR health literacy [MeSH] OR information literacy [MeSH] OR secondary prevention [MeSH] OR patient education [MeSH] OR health education [MeSH] OR information provision
D – Design	Interview
E – Evaluation	Experience
R – Research type	qualitative OR mixed method* OR findings
Search combination: S AND PI AND (D OR E OR R)	

*Adaption of search terms for each database.

Supplementary Table 2

Example of the search strategy in CINAHL

CINAHL via EBSCOhost (27th November 2016, update 24th July 2018)

SPIDER Tool	Search terms
S – Sample Hits: 59560 Update hits: 5732	– (myocardial infarction [MH] OR heart attack [TX] OR acute coronary syndrome [MH]) OR – (coronary disease [MH] OR coronary heart disease [TX] OR coronary artery disease [TX]) OR – (myocardial revascularization [TX] OR percutaneous coronary intervention [TX] OR angioplasty coronary [TX] OR percutaneous transluminal coronary angioplasty [TX] OR fibrinolysis [TX] OR coronary artery bypass [TX] OR coronary artery bypass grafting [TX])
PI – Phenomenon of Interest Hits: 57439 Update hits: 5732	– (“risk communication” [TX] OR “health communication” [TX] OR “risk perception” [TX] OR “risk interpretation” [TX] OR “risk framing” [TX] OR “risk literacy” [TX] OR health literacy [MH] OR information literacy [MH]) OR – “secondary prevention” [TX] OR – (patient education [MH] OR health education [MH] OR information provision [TX])
D – Design E – Evaluation R – Research type Hits: 363782 Update hits: 52117	(interview [TX]) OR “patient* experience” [TX] OR qualitative [TX] OR “mixed method*” [TX] OR finding* [TX]



Limit 1996-2016: **410**
Update 2016-2018: **33**

Supplementary Table 3
Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ)

Item	Response
1. Aim	The aim of this study is to explore how people with coronary heart disease and/or a history of an acute myocardial infarction, experience health education and risk communication.
2. Synthesis methodology	Thematic synthesis (Thomas & Harden, 2008). Data on risk communication consisted of concepts and themes related to the topic which were situated within studies of different phenomena. For this reason we decided these data were not amenable to the sort of context-bound interpretations that characterise meta-ethnography.
3. Approach to searching	A pre-planned exhaustive search in five key databases was completed to seek all available published studies.
4. Inclusion criteria	<p>Population: Patients with a history of acute myocardial infarction (AMI) and confirmed coronary heart disease (CHD)</p> <p>Study type: Articles reporting qualitative research involving both qualitative methods of data collection and analysis.</p> <p>Language: English and German</p> <p>Year limits: 1996 - November 2016 (Update by July 2018)</p> <p>Type of publication: No filter applied for type of publication in the databases</p>
5. Data sources	<p>Databases: Cochrane Library; CINAHL; MEDLINE/PubMed; PsycINFO; SSCI</p> <p>Hand searching was not conducted.</p>
6. Electronic search strategy	<p>See supplementary Tables 1 and 2</p> <p>MeSH terms and key words for qualitative research were applied.</p>

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Item	Response
7. Study screening methods	<p>A review of titles and abstracts retrieved against the pre-determined inclusions criteria was completed by two independent reviewers.</p> <p>The full texts were screened and classified as 'include', 'maybe' or 'exclude' by two independent reviewers. Disagreements were resolved by a third reviewer.</p> <p>Covidence software was used for independent screening.</p>
8. Study characteristics	<p>Supplementary Table 4 presents the characteristics of the included studies subdivided in author, year of publication, country, study aim, participants, methodology and data collection and data analysis method.</p>
9. Study selection results	<p>PRISMA Flowchart (including update); see supplementary Figure 1</p>
10. Rationale for appraisal	<p>Quality appraisal was completed to evaluate how the principles and assumptions underpinning qualitative research are reflected in the included studies informing the synthesis.</p>
11. Appraisal items	<p>The Critical Appraisal Skills Programme (CASP) qualitative checklist was used as it addresses the underpinning principles and assumptions of the study.</p>
12. Appraisal process	<p>Item 3-10 of CASP checklist were independently judged by two reviewers in Covidence. Disagreements were discussed until consensus was reached. In one case the judgement of a third reviewer was needed.</p>
13. Appraisal results	<p>Papers were not excluded on the grounds of quality but provided an overview of the quality of the included studies as to ascertain the believability of results.</p> <p>Supplementary Figure 2 shows a summary of the appraisal for each included study.</p>
14. Data extraction	<p>Three reviewers undertook independent coding. Participant quotes, themes, discussions and conclusions from the original authors were extracted into NVivo by two reviewers. A third reviewer cross-checked paper versions independently. Data pertaining to the authors, year of publication, country, aims, participants, methodology, sampling, data collection, analysis and interpretation were extracted by one author into a table in Microsoft Word.</p>
15. Software	<p>NVivo 11 and Covidence</p>

Item	Response
16. Number of reviewers	3
17. Coding	The authors began by importing concepts from seminal studies, which were identified by quality appraisal and the number of citations within the literature. Then, three reviewers coded individual study findings on risk communication, noting key themes, and staying as close to the data as possible.
18. Study comparison	In the first stage of analysis, themes were 'close' to the data. These low-level themes from individual studies were compared in discussions among the research team, and using the cluster analysis function in NVivo. The aim of the comparisons was to understand what the corpus of data as a whole was telling us about risk communication experiences.
19. Derivation of themes	Themes were derived using a mixture of 'top down' and 'bottom-up' analysis. Concepts from seminal studies were used to guide the synthesis in the first instance, and at the same time new themes were created to describe any data that did not fit into these. Then, these descriptive themes were inspected for similarities and differences, with the aim of creating higher-order clusters of themes. Finally, through discussions among the research team, we generated analytical themes – abstract themes that were capable of explaining and understanding all the initial, descriptive themes. Throughout this process, we only focused on data within the original studies that specifically pertained to risk communication and health education. A fourth member of the team as checked back all citations in the final results.
20. Quotations	Participant quotations and authors' interpretations are provided with the results section of the review to illustrate the themes and categories.
21. Synthesis output	New interpretations of the data have identified 3 themes with 10 categories and are displayed in supplementary Table 5.

Supplementary Table 4

Summary of included studies

Authors, year, country	Study aim	Participants	Methodology, data collection	Data analysis method
(Abramsohn et al., 2013) USA	To understand female sexual recovery following an AMI and to inform design of an evidence-based strategy to improve female sexual outcomes after AMI.	Subsample of 17 female participants drawn from a larger sample (n = 76) of eligible participants (reported sexual activity in the year before AMI) recruited to a longitudinal study. Median (range) age: 58 (43 - 75) yr.	Grounded theory, Purposive random sampling, semi-structured telephone interviews within 18 mo. of study completion or 30 mo. of AMI.	Content analysis
(Askham et al., 2010) Faroe Islands	To explore women's experiences of hospitalization for acute coronary syndrome and their information and support needs.	8 women admitted to hospital with diagnosis of ACS (AMI n=7; unstable angina pectoris n=1). Mean (range) age: 61.5 (48-70) yr.	Naturalistic enquiry, Purposive sampling, Semi-structured face-to-face interviews within 3-4 weeks of hospitalization with first known ACS events.	Thematic analysis
(Astin, Closs, McLenachan, Hunter, & Priestley, 2008) UK (England)	To explore the information needs of patients treated with angioplasty for heart attack.	29 participants admitted to hospital for primary percutaneous coronary intervention (PCI). Mean (range) age: 60 (36 – 83) yr. 59% male.	Qualitative methods as part of a larger mixed methods study, purposive sampling, semi-structured face-to-face interviews within 3 – 12 days of hospital discharge.	Framework analysis
(Attebring, Herlitz, & Ekman, 2005) Sweden	To explore patients' experiences of secondary prevention after experiencing a first time AMI.	20 participants following an AMI. Median (range) age: 61.5 (34 – 79) yr. 60% male.	Hermeneutical qualitative methodology, face-to-face interviews using a narrative approach conducted at a median of 7.5 wk after discharge.	Hermeneutic approach
(Cartledge, Feldman, Bray, Stub, & Finn, 2018) Australia	1. To gain a comprehensive perspective about the experience of patient and spousal education following an acute cardiac event. 2. To elicit an understanding from cardiac patients and their spouses of their attitudes,	12 cardiac patients and their spouses/partners Patients: 9 men/3 women with STEMI (5), NSTEMI (5), Takotsubo (2) Mean age (range): 62 (47-75) yr. Spouses/partners: 3 men/9 women	Qualitative, phenomenological approach, TPB (Theory of Planned Behaviour) Data collection: clinical data, survey data, semi- structured interviews conducted at 4-6 weeks after discharge, field notes	Thematic analysis

Authors, year, country	Study aim	Participants	Methodology, data collection	Data analysis method
	preferences and intentions towards future CPR training.	Mean age (range): 59 (42-72) yr.		
(Chan & Lopez, 2014) Hong Kong	To explore Hong Kong Chinese people's knowledge, perceptions, and risk control behavior and strategies.	100 participants with either low-risk of CHD (57), multiple coronary risk factors (27) or had experienced an AMI and had undergone a cardiac rehabilitation program (21). 52% male. Mean (SD, range) age: 56.5 (20.1, 18 – 88) yr.	18 single-gender focus groups (10 for low-risk group and 4 each for risk factors and AMI participants). Convenience and snowball sampling.	Content analysis
(Crane, 2001) USA	To explore how women gain knowledge of secondary prevention after AMI without attending cardiac rehab and identify barriers to receiving this information.	15 women following a AMI. Age range: 66 – 88 yr. 60% white, 67% had ≤high school education.	Descriptive naturalistic study, 1 face-to-face interview and telephone interview within 3 to 12 months after AMI.	Content analysis, constant comparison method
(Doyle, Fitzsimons, McKeown, & McAloon, 2012) UK (N. Ireland)	To explore factors that influence dietary choices by patients attending cardiac prevention clinics after AMI.	9 participants with a history of AMI attending cardiac prevention clinics with BMI >25 kg/m ² for >6 months. 56% male. Age range: 49 – 69 yr.	Interpretive phenomenology, purposive sampling, semi-structured face-to-face interviews.	Colaizzi's (1978) phenomenological analysis
(Dullaghan et al., 2014) UK (N. Ireland)	To explore and compare patients' illness perceptions and motivation for behavioral change following AMI treated by different methods.	15 participants with AMI treated with primary PCI (5), PCI (5), thrombolysis (5). Age range: 44 – 73 yr. 73% male.	Qualitative component of a larger mixed methods study, stratified, purposive sampling, face-to-face semi-structured interviews.	Framework analysis
(Everett, DiGiacomo, Rolley, Salamonsen, & Davidson, 2011) Australia	To explore patients' thinking, understanding, behaving to changing behavior and the factors that influence adoption of a healthier lifestyle.	25 participants attending 3 cardiac rehabilitation programs after an acute cardiac event. 64% male. Mean age: 61 yr.	Motivational interviewing in which participants identified an area of behavior change that they wished to address. 25 participant transcripts were chosen at random for analysis.	Thematic analysis
(Gambling, 2003) UK (England)	To understand the informational needs of patients with CHD and the factors	Approximately 40 participants from a sample of 200 people attending a coronary heart rehabilitation self-help	Five focus groups (6-8 participants in each), purposive sampling.	Thematic analysis

Authors, year, country	Study aim	Participants	Methodology, data collection	Data analysis method
	perceived important in reducing CHD risk.	group with age range 32 – 85 yr. Participants previously had a MI or angina. Male: female ratio of 5:1.		
(Goldsmith, Lindholm, & Bute, 2006) USA	To explore the dilemmas that may arise when couples talk about lifestyle changes following one person's AMI or CABG.	25 participants (84% male) who had experienced an AMI (6), CABG (8) or both (11) and 16 female partners. Patients' mean age: 66 yr. Partners' mean age: 63 yr.	Grounded theory, face-to-face interviews	Open coding methods of grounded theory
(Gulanick, Bliley, Perino, & Keough, 1998) USA	To explore patients' responses, barriers and facilitators to suggested lifestyle changes for risk reduction following coronary angioplasty.	45 participants who had undergone angioplasty within previous 3 to 18 months. 29% had PCI at the time of AMI 59% male. Mean (range) age range: 61 (34 – 74) yr.	7 focus groups (4 to 9 participants in each), convenience sampling	Thematic analysis and constant comparative method
(Hagberth, Sjoberg, & Ivarsson, 2008) Sweden	To explore the experiences of women over 70 years taking part in a patient group education program after PCI.	13 women treated with PCI and attended a patient group education program. Mean (range) age: 78 (73 – 87) yr. Time between cardiac event and group education (range): 3 – 15 months.	Qualitative descriptive design, 3 focus groups (4 to 6 participants in each)	Content analysis
(Hansen & Nelson, 2011) Australia	To understand the views of patients with ACS on smoking behavior and its association with coronary artery disease.	32 participants who had been hospitalized in previous year with acute angina or AMI. 18 (11 male) were smokers and 14 (12 male) had quit smoking since discharge. Median (range) age: 57 (40 – 74) yr. 72% male.	Grounded theory, face-to-face semi-structured interviews.	Grounded theory, constant comparison
(Hanssen, Nordrehaug, & Hanestad, 2005) Norway	To explore patients' information needs and follow-up preferences after discharge following AMI.	14 participants recently discharged from hospital following AMI. 86% male. Age range: 42 – 69 yr.	Qualitative and exploratory approach, participants attended one of 3 focus groups.	Content analysis
(Jensen & Petersson, 2003) Denmark	To explore patients' experiences of illness after first AMI.	30 participants following a first AMI. 73% male. Mean (range) age: 60 (41 – 80) yr. All women were either housewives or pensioners.	Qualitative, face-to-face semi-structured interviews conducted during hospitalization and in cardiac outpatient clinics 17 weeks after hospital admission.	Content analysis and relations to the Perception Model identified.

Authors, year, country	Study aim	Participants	Methodology, data collection	Data analysis method
(Kerr et al., 2010) UK (England)	To explore experiences of using a web-based intervention in CHD patients.	19 participants with diagnosis of CHD recruited in primary care. 68% male. AMI only (4), AMI and angina (4), Angina only (9), CHD without angina or AMI (2) Time since earliest CHD diagnosis (mean, SD, range): 9.8, 6.5, 1 – 22 yr.	Qualitative component of a larger study, face-to-face semi-structured interviews.	Thematic analysis
(King, Thomlinson, Sanguins, & LeBlanc, 2006) Canada	To explore the influence of gender and culture on the processes people with Euro-Celtic heritage undergo when making lifestyle changes associated with their CAD risk.	42 participants with CAD, 18 with AMI 52% male. 21 Urban-living mean (range) age Male: 65 (47 – 83) yr. Female: 62 (39 – 75) yr. 21 Rural-living mean (range) age Male: 64 (48 – 75) yr. Female: 61 (42 – 81) yr.	Grounded theory, purposive sampling, face-to-face and telephone semi-structured interviews.	Grounded theory, constant comparison, open coding and theory development
(King, Sanguins, McGregor, & LeBlanc, 2007) Canada	To explore the influence of gender and culture on the processes Canadian First Nations people undergo when making lifestyle changes associated with their CAD risk.	22 participants of Canadian First Nations heritage with CAD, majority with a history of a cardiac event e.g. AMI Age range: 44 – 79 yr. Most had high-school education.	Grounded theory, purposive sampling, face-to-face and telephone semi-structured interviews.	Grounded theory, constant comparison, open coding and theory development
(Kristofferzon, Lofmark, & Carlsson, 2007) Sweden	To explore the experiences of managing problems, coping, social support and quality of life following an AMI.	39 participants who had experienced AMI four to six months earlier. 49% male. Age mean (SD; range): Male: 65 (11; 47-88) yr. Female: 66 (11; 48-90) yr.	Qualitative, face-to-face semi-structured interviews.	Content analysis
(McSweeney & Crane, 2001) Canada	To understand women's decision-making process and the factors that help them overcome barriers and facilitate their continuation in cardiac rehabilitation.	40 women who had experienced their first AMI in previous 6 weeks to 12 months. 14 women attended rehab and 26 did not. Mean (SD) age: 58.5 (12.5) yr.	Descriptive, naturalistic study, purposive sampling, guided in-depth interviews.	Content analysis and constant comparison
(Moore, Kimble, & Minick, 2010) USA	To explore the perceptions of risk and behaviors to reduce risk in women with CHD.	7 female participants diagnosed with CHD (AMI 14,3%, coronary stenting 71,4%) Mean (SD) age: 69 (13) yr	Interpretive phenomenology, face-to-face semi-structured interviews	Interpretive coding to generate categories and themes.

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Authors, year, country	Study aim	Participants	Methodology, data collection	Data analysis method
(Mosack & Steinke, 2009) USA	Explore sexual concerns of patients after AMI between 1995 and 2002.	302 patients after AMI from 3 separate studies. Study 1: n=96, 54% male. Study 2: n=91, 76% male. Study 3: n=115, 80% male.	Open-ended survey questions with narrative comments collected between 1 to 6 months after AMI.	Secondary content analysis of qualitative data from 3 previous studies.
(Murie, Ross, Lough, & Rich, 2006) UK (Scotland)	To explore patients' views and opinions on informational needs that would assist their involvement in decision making and problem solving after an AMI.	6 post-AMI patients. 83% male. Age range: 45 – 68 years.	Participants reviewed 46 existing interventions and took part in a focus group.	Framework analysis.
(Pryor, Page, Patsamanis, & Jolly, 2014) Australia	To identify the support required by patients after completing a cardiac rehabilitation program following an AMI.	9 Patients within 4 – 12 months after completing cardiac rehabilitation and 12 weeks – 14 months after a cardiac event. 44% male. Age range at time of cardiac event: 39 – 71 yr.	Individual telephone semi-structured interviews.	Constant comparative method involving open coding.
(Romppel, Gunold, Schubmann, Richter, & Grande, 2013) Germany	To examine suitable settings, organizational structures, contents and methods from patients' perspectives to achieve sustainable lifestyle modification in coronary heart disease.	60 patients after first cardiac event defined as myocardial infarction and/or myocardial revascularization (bypass or PCI) 72% male Age range: 35-86 Mean 64.8 yr.	10 focus group interviews (acute setting n=3, cardiac rehabilitation n=3, at least 6 months after cardiac event n=4) .	Content analysis.
(Ruston & Clayton, 2002) UK (England)	To examine the ways women use the concept of risk to predict and explain their likelihood of developing CHD.	Group 1: 50 women admitted to hospital with CHD-related cardiac event. Group 2: 33 women without CHD, admitted to hospital for routine, elective procedures.	Face-to-face interviews during hospitalization (majority on 3 rd or 4 th day of admission).	Coding using the constant comparative method.
(Simony, Dreyer, Pedersen, & Birkelund, 2015) Denmark	To explore the experiences of patients with CHD during and after participating in cardiac rehabilitation.	11 participants diagnosed with CHD between 1 to 14 months earlier (8 NSTEMI, 3 unstable angina) Male: 82% Mean (range) age: 66 (59 – 87) yr.	Ethnography, field observations, semi-structured 2 focus groups (4 or 5 participants in each) and individual face-to-face interviews 1-2 months after the focus groups.	Three-phased phenomenological-hermeneutic approach.

Authors, year, country	Study aim	Participants	Methodology, data collection	Data analysis method
(Smith, Frazer, Hall, Hyde, & O'Connor, 2017) Republic of Ireland	To investigate experiences of women with a primary diagnosis of ACS (NSTEMI and unstable angina) in the 6-8 week period following discharge from hospital and the mediating impact of a newly-diagnosed disease.	30 women (19 NSTEMI, 11 unstable angina) Age range: 36–81 yr.	Naturalistic case study (within-case study followed by cross-case analysis), Participant diaries (19) and in-depth, face-to-face interviews (30).	Within-case study followed by cross-case analysis, modified analytic induction (MAI).
(Svavarsdottir, Sigurdardottir, & Steinsbekk, 2016) Norway and Iceland	To explore patients with CHD perceptions of a good educator following participation in patient education after PCI.	17 participants (11 Icelandic & 6 Norwegian) with CHD, 14 primary PCI, 3 elective PCI 53% male. Mean (range) age: 59 (47 – 72) yr. Mean (range) duration since PCI: 6.5 (1.5 – 19) months.	Qualitative, purposive sampling, face-to-face semi-structured interviews.	Systematic text condensation to identify themes and concepts
(Treloar, 1997) Australia	To explore the experiences of patients with heart disease.	20 participants with heart disease (n=6 AMI). 65% male.	Qualitative, face-to-face semi-structured interviews	Thematic analysis
(Wang, Thompson, Chair, & Twinn, 2008) China	To explore Chinese patients' and partners' experiences during early convalescence from a first heart attack.	17 Chinese dyads (AMI survivors and their partners). 82% male. Age mean, SD (range): 57+8.6 (39-73) yr.	Three focus groups guided by an open-ended interview schedule.	Phenomenological techniques and content analysis to develop categories.
(Webster, Thompson, & Mayou, 2002) UK (England)	To explore the experiences and needs of Gujarati Hindu AMI patients and their partners in the first month after an AMI.	35 Gujarati Hindu participants following an AMI. 71% male. Mean age: 65 yr.	Qualitative, theoretical sampling, semi-structured face-to-face interviews, 2 to 3 weeks after discharge from hospital.	Coding and constant comparison to develop categories
(White, Bissell, & Anderson, 2010) UK (England)	To explore CHD patients' perspectives and lifestyle changes following a hospital-based cardiac rehabilitation program.	15 white British patients with CHD, 3 months following cardiac rehabilitation. 73% male. Mean (range) age: 57 (42 – 72) yr.	Qualitative, in-depth interviews 3 months after cardiac rehabilitation and follow-up interview 9 months later with 10 participants.	Thematic analysis
(Wiles & Kinmonth, 2001) UK (England)	To explore patients' understandings of an AMI and ways that secondary prevention services could be designed.	25 participants following admission to hospital with diagnosis of AMI. 52% male.	Qualitative, maximum variation sampling, in-depth face-to-face interviews at 2 weeks and 4 months after hospital discharge.	Grounded theory approach using line by line coding to generate themes

Authors, year, country	Study aim	Participants	Methodology, data collection	Data analysis method
(Wiles, 1998) UK (England)	To explore peoples' understandings and beliefs about heart attacks and recovery following a first AMI.	25 participants following first AMI. 52% male. Age range: 34 – 80 yr. Participants received a pilot intervention involving a visit from a cardiac nurse who provided information about heart attack causes, recovery and lifestyle changes and arranged follow-up with practice nurse.	In depth semi-structured interviews at 2 weeks after hospital discharge and 3 months later. Maximum variety sampling from sub-sample of people taking part in larger intervention study	Grounded theory, open coding and theory development
(Woodard, Hernandez, Lees, & Petersen, 2005) USA	To explore the cardiovascular health care experiences and beliefs of African-American and white patients with CHD.	24 (14 white, 10 African-American) male participants with CHD. Group 1: 8 white males, 56 – 75 yr. Group 2: 6 white males, 57 – 68 yr. Group 3: 4 African-American males, 48 – 83 yr. Group 4: 6 African-American males, 52 – 80 yr.	Qualitative, 4 focus groups with different participants	Thematic analysis
(Wright, Wiles, & Moher, 2001) UK (England)	To understand patients' post-AMI and practice nurses' views of nurse-led clinics on secondary prevention of ischemic heart disease in primary care.	22 participants with ischemic heart disease attending the nurse-led clinic intervention. Age range: 55 – 76 yr. 64% male. Duration since diagnosis (range): 5 – 20 yr. Mixed social classes. 6 Practice nurses. Age range: 38 – 61 yr.	Qualitative sub-study of larger trial comparing 3 methods of promoting secondary prevention of ischemic heart disease. Theoretical sampling of patient participants. 1 focus group with nurses and individual face-to-face interviews with patients after 1 to 10 days after the clinic. Audio recordings of clinic consultation with nurse.	Thematic analysis
(Yamada & Holmes, 1998) Canada	To explore patients' experiences with an in-hospital, post-AMI teaching program.	6 participants with diagnosis of AMI and currently hospitalized. 83% male. Mean (range) age: 56 (49 – 87) yr.	Hermeneutic (interpretive) phenomenology, purposive sampling, 2 focus groups (3 participants in each).	Three-phased phenomenological-hermeneutic approach involving content analysis

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Supplementary Table 5 Themes and categories

Themes	Categories
Patients' experiences of communication and health education interactions with health professionals	Patient participation in educational interactions
	Finding a common language
	Open dialogue
	Conflicting and confusing risk communication
Patients' views and preferences for risk and secondary prevention information and education	Empathic interactions
	Modality, timing and amount of information and education
	Generic information
Patients' perceptions about "cardiac" risk	Missing information
	Fear of myocardial infarction recurrence
	Feeling fixed and cured

Supplementary Table 6

Themes and categories by article matrix

Themes	Patients' views and preferences for risk and secondary prevention information and education			Patients' experiences of communication and health education interactions with health professionals					Patients' perceptions about 'cardiac' risk	
	Modality, timing and amount of information and education	Generic information	Missing information	Finding a common language	Conflicting and confusing risk communication	Empathic interactions	Open dialogue	Patient participation	Fear of recurrent MI	Feeling fixed and cured
Abramsohn et al., 2013	✓	✓	✓	✓	✓		✓	✓	✓	
Askham et al., 2009	✓	✓	✓	✓		✓	✓		✓	
Astin et al., 2008	✓	✓	✓	✓	✓		✓	✓	✓	✓
Attebring et al., 2005	✓	✓	✓	✓	✓		✓	✓	✓	
Cartledge et al., 2018			✓		✓		✓	✓		
Chan & Lopez, 2014	✓		✓	✓				✓	✓	
Crane, 2008	✓	✓	✓	✓	✓		✓	✓		
Doyle et al., 2010		✓	✓	✓	✓				✓	✓
Dullaghan et al., 2014					✓				✓	✓
Everett et al., 2011	✓				✓					✓
Gambling, 2003	✓	✓	✓	✓	✓			✓	✓	
Goldsmith et al., 2006					✓				✓	
Gulanick et al., 1998	✓		✓		✓				✓	✓
Hagberth et al., 2007			✓	✓			✓	✓	✓	
Hansen & Nelson, 2011			✓		✓	✓	✓	✓		✓
Hanssen et al., 2005	✓	✓	✓		✓	✓		✓	✓	
Jensen & Petersson, 2003	✓		✓		✓	✓		✓	✓	
Kerr et al., 2010	✓	✓					✓	✓		
King et al., 2006	✓			✓					✓	
King et al., 2007	✓			✓				✓		
Kristofferzon et al., 2005	✓	✓	✓		✓	✓	✓	✓	✓	

Themes	Patients' views and preferences for risk and secondary prevention information and education			Patients' experiences of communication and health education interactions with health professionals					Patients' perceptions about 'cardiac' risk	
Categories	Modality, timing and amount of information and education	Generic information	Missing information	Finding a common language	Conflicting and confusing risk communication	Empathic interactions	Open dialogue	Patient participation	Fear of recurrent MI	Feeling fixed and cured
McSweeney & Crane, 2001	✓	✓	✓			✓				
Moore et al., 2010							✓	✓	✓	
Mosack & Steinke, 2009	✓		✓		✓		✓		✓	
Murie et al., 2006	✓	✓		✓	✓		✓			
Pryor et al., 2013	✓			✓						
Romppel et al. 2013	✓	✓			✓		✓			
Ruston & Clayton, 2002					✓				✓	
Simony et al., 2015		✓				✓	✓			
Smith et al., 2017	✓		✓		✓	✓			✓	✓
Svavarsdóttir et al., 2016	✓	✓		✓		✓	✓	✓	✓	
Treloar, 1997	✓	✓				✓	✓		✓	
Wang et al., 2008		✓	✓		✓			✓	✓	
Webster et al., 2002	✓		✓	✓					✓	
White et al., 2010		✓			✓	✓		✓	✓	
Wiles & Kinmonth, 2001	✓				✓			✓		✓
Wiles, 1998	✓	✓	✓		✓				✓	✓
Woodard et al., 2005				✓	✓	✓		✓	✓	
Wright et al., 2001	✓		✓	✓		✓		✓		
Yamada & Holmes, 1998	✓	✓	✓		✓	✓		✓		