

# Ethical issues in cardiovascular risk management: Patients need nurses' support

Citation for published version (APA):

Koelewijn-van Loon, M. S., van Dijk-de Vries, A., van der Weijden, T., Elwyn, G., & Widdershoven, G. A. M. (2014). Ethical issues in cardiovascular risk management: Patients need nurses' support. *Nursing Ethics*, 21(5), 540-553. <https://doi.org/10.1177/0969733013505313>

## Document status and date:

Published: 01/01/2014

## DOI:

[10.1177/0969733013505313](https://doi.org/10.1177/0969733013505313)

## Document Version:

Publisher's PDF, also known as Version of record

## Document license:

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# Ethical issues in cardiovascular risk management: Patients need nurses' support

Nursing Ethics  
2014, Vol. 21(5) 540–553  
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10.1177/0969733013505313  
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## Abstract

Involving patients in decisions on primary prevention can be questioned from an ethical perspective, due to a tension between health promotion activities and patient autonomy. A nurse-led intervention for prevention of cardiovascular diseases, including counselling (risk communication, and elements of shared decision-making and motivational interviewing) and supportive tools such as a decision aid, was implemented in primary care. The aim of this study was to evaluate the nurse-led intervention from an ethical perspective by exploring in detail the experiences of patients with the intervention, and their views on the role of both the nurse and patient. The study had a qualitative design. 18 patients who had received the intervention participated. Data were gathered by in-depth interviews. The interviews were analysed using directed content analysis. The findings revealed that patients perceived the consultations not as an infringement on their autonomy, but as supportive to risk reduction efforts they tried but found hard to realise. They specifically emphasised the role of the nurse, and appreciated the nurse's realistic advice, encouragement, and help in understanding. Patients' views on and experiences with risk management are in line with notions of relational autonomy, caring cooperation and communicative action found in the literature. We conclude that patients define the relationship with the nurse as shared work in the process of developing a healthier lifestyle.

## Keywords

Cardiovascular diseases, ethics, motivational interviewing, nurse-led care, primary prevention, qualitative research, shared decision-making

## Introduction

Guidelines on the primary prevention of cardiovascular diseases (CVDs) recommend, in addition to medical treatment for high-risk patients, education and counselling on smoking, diet, physical exercise and alcohol consumption for patients with moderate to severe increased risk for CVD.<sup>1</sup>

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We face the huge problem of the patient's adherence to lifestyle advice and medication that is about 50%, ranging from 20% to 90%.<sup>2,3</sup> Making decisions in cardiovascular risk management (CVRM) is, however, complex, as often more than one risk reduction option is available. Imagine Mr Jones, he is 62 years old, smokes, his body mass index (BMI) is 32 and his physical exercise level averages 10 min per day. His systolic blood pressure is 160 mmHg, and his total/high-density lipoprotein (HDL) cholesterol ratio is 6. He could give up smoking and try to lower his blood pressure or lower his cholesterol ratio, or a combination of these interventions. The choice is even more complex, as blood pressure and cholesterol could be improved by medication, by improvements in lifestyle (diet, physical activity and stopping smoking) or by a combination of these interventions.

In addition to this complexity, the Dutch CVRM guideline recommends involving patients in the decision-making process about cardiovascular risk reduction without, however, clarifying how this can be done. Shared decision-making (SDM) is defined as the process in which (1) at least two parties are involved in the process of decision-making, (2) both parties share information from their different perspectives, (3) both parties take steps to decide on the preferred course of action and (4) both parties agree with the decision (which may involve doing nothing).<sup>4</sup> Applying the principles of SDM seems to be difficult, and they are less widely applied than intended.<sup>5-8</sup>

We designed a nurse-led intervention aimed at improving lifestyle and reducing cardiovascular risk through patient involvement in the decision-making process on risk reduction. This intervention is composed of elements of risk assessment, risk communication, adapted motivational interviewing and a patient decision aid exposing all the pros and cons per option in neutral language.<sup>9</sup> Primary prevention of CVDs is increasingly delegated to practice nurses in primary care.<sup>10</sup> Not only are nurses seen as valuable contributors to the task of lifestyle counselling, delegation to practice nurses is also seen as a valuable option for risk communication and decision-making.<sup>11</sup> See Box 1 for the key features of the intervention. The effects of the intervention on cardiovascular risk, lifestyle and risk perception are published elsewhere.<sup>20,21</sup>

#### CONSULTATION 1 *talk about choice and options*

**(1) Risk assessment:** The absolute 10-year mortality and morbidity risk from cardiovascular diseases was assessed with the help of a risk table from the Dutch guideline (non-diabetes patients) or the UK Prospective Diabetes Study (UKPDS) risk engine (diabetes patients)<sup>12,13</sup> (after which control-group nurses continued with 'usual care').

**(2) Risk communication:** The absolute 10-year cardiovascular risk was communicated to patients with a risk communication tool developed for this study, using various risk formats, like natural frequencies, relative risk and a population chart.<sup>14,15</sup>

**(3) Use of a patient decision aid:** A decision aid was handed over to the patients to consider options for risk reduction at home. The decision aid developed by Van Steenkiste<sup>16</sup> was updated. The aid facilitates the process of interacting with patients in order to arrive at an informed, values-based choice for risk reduction. It contains the risk tables and provides information about the options and their associated relevant outcomes.

#### CONSULTATION 2 *talk about options, values and decision-making*

**(4) Adapted motivational interviewing (MI):** The agenda was set in the spirit of MI (with the help of an agenda-setting chart with illustrative drug- and lifestyle-related icons). The nurses explored importance and built confidence by asking the patients questions (with help of the strategies 0-10 scale, examining the pros and cons and brainstorming about solutions). The options for risk reduction were discussed and considered, and personal values were elicited using 'adapted MI'. MI is a directive, client-centred counselling style helping clients explore and resolve ambivalence about behaviour change.<sup>17</sup> Adapted MI has been used to assess patients' motivations for behaviour change and build

motivation for healthy behaviours, to clarify values; to achieve goal setting and concrete action plans and to reveal both positive and negative consequences of behaviour change.<sup>18,19</sup>

TELEPHONE CONSULTATION *talk about implementation of the decision*

**(4) Adapted MI:** The nurses applied MI; set an agenda; explored importance and built confidence. Nurses guided the patients in formulating or reformulating the main personal goals for lifestyle change, supported them and/or referred them to local facilities. This consultation was a follow-up to consultation 2.

**Box 1.** Key features of the nurse-led intervention to improve lifestyle adherence in CVRM.

The combination of motivational interviewing and SDM can be questioned from an ethical perspective, as there is a tension between health-promotion activities and patient autonomy. Healthcare professionals hold the view that in many situations, the scientific evidence for benefit of a healthy lifestyle strongly outweighs harm,<sup>22</sup> but non-compliance to lifestyle advice is a challenge,<sup>23</sup> and patients who do not adhere to the doctor's advice are usually seen as deviant.<sup>24</sup> Also communication of risks needs ethical reflection. Does risk communication actually enable patients to make well-considered decisions? Providing information on risks and advantages and disadvantages of treatment options involves a number of difficulties, which can lead to the situations where patients are provided incomplete and inaccurate information.<sup>25</sup>

Given the tension between health-promotion activities and patient autonomy, and the difficulties with risk communication regarding the ability of patients to make their own decisions and shape their own life, several ethical questions came up during the design of the intervention: What do patients consider as a good nursing intervention, which is not overruling their autonomy, but also not leaving them without support? What do patients expect from the nurse-patient relationship? How do patients experience the patient involvement intervention, and is that in line with their views on a good nurse-led intervention and expectations from the nurse-patient relationship? The aim of this study was to evaluate the nurse-led intervention for primary prevention of CVDs from an ethical perspective, by exploring in detail the experiences of patients with the intervention, and their views on the role of both the nurse and patient.

## Methods

In-depth interviews were conducted with patients who had received the intervention to investigate their experiences with being involved in nurse-led CVRM in primary care.

### Setting and sample

The intervention was implemented in 13 general practices in the south of the Netherlands in 2006. It was evaluated in a cluster-randomised controlled trial. All participants of the intervention study in these practices were eligible for a cardiovascular risk assessment but had no existing CVDs.

We wanted to interview patients who had received the intervention as intended, that is, in which patient involvement was promoted. Therefore, we selected five practice nurses of the intervention group who had performed well in terms of applying the intervention. These nurses were selected on the basis of observations during their training, and audiotaped consultations during the trial. The nurses were asked to invite patients with a certain profile for an interview, to ensure that the sample included enough variation in terms of the patients' age, sex and risk factors. We specifically explained to the nurses that patients did not have to be successful in terms of lifestyle change, as long as the elements of the intervention (risk communication, patient decision aid and adapted motivational interviewing) had been applied. If a patient agreed to

**Table 1.** Characteristics of participants.

Interview	Sex	Age (years)	Diabetes, yes/no	Cardiovascular risk profile: 10-year cardiovascular mortality risk <sup>a</sup>
1	M	69	Yes	14%
2	M	75	No	21%
3	F	62	No	3%
4	F	57	No	2%
5	F	53	No	1%
6	F	60	No	11%
7	F	62	No	10%
8	M	68	Yes	13%
	F	68	No	6%
9	F	76	No	3%
10	M	63	Yes	16%
	F	56	No	2%
11	M	57	Yes	10%
12	M	46	No	1%
13	F	67	No	8%
14	F	53	No	2%
15	M	60	No	15%
16	F	60	No	6%

UKPDS: UK Prospective Diabetes Study; SCORE: Systematic Coronary Risk Evaluation.

<sup>a</sup>Calculated with SCORE<sup>26</sup> for patients without diabetes and with the UKPDS<sup>13</sup> for patients with diabetes.

participate, the nurse passed the patient's name and address to the principal researcher. The interviewer invited the patients again by letter, and contacted them by phone to make an appointment for an interview. We invited patients till data saturation was reached.

Patients gave oral consent after being informed about the study by the interviewer before the start of the interview. All patients participated on a voluntary basis. The trial was approved by the research ethics committee of the Academic Hospital Maastricht and Maastricht University (MEC 04-259.3).

A total of 18 patients were interviewed in 16 interviews. Two interviews were conducted with married couples who had consulted the practice nurse. Table 1 shows the characteristics of the participants.

### Data collection

A total of 16 interviews were conducted between May and September 2006, all at the patients' homes. The interviews generally lasted 40 min (range = 22–58 min).

An interview guide was used as an aid to ensure that all relevant topics were discussed. The interview guide included open questions to explore the patients' experiences with the nurse-led consultations. The interview questions of this study regarded the patient's expectations, experiences and preferences for the future with regard to (1) the role of the patient, (2) the role of the nurse and (3) the significance of the consultation. See Appendix 1 for the interview questions. After an interview had been analysed, the interview guide and interview style could be adapted and improved for the next interview.

The interviews used a dialogue style,<sup>27</sup> a format in which truth is seen as the outcome of a merger of perspectives. The interviewer tried to get access to the patient's story, by adopting an attitude which was both involved and personal. The interviewer did not know the nurses and did not have any conflict of interest

**Table 2.** Overview of authors' contribution.

Research phase	Who <sup>a</sup>	Note
Selection of nurses for patient recruitment	MK	Based on observations during the training and recordings of consultations during the trial
Patient recruitment	Nurses	Each nurse invited 2–4 patients for participation in an interview
Data collection	AvD	16 interviews at patients' homes
Transcriptions of interviews	AvD	
Data coding and first analysis	AvD and MK	
Data analysis and interpretation	AvD, MK, TvdW and GW	
Draft paper	MK	
Revised paper	AvD, GW, GE and TvdW	

<sup>a</sup>MK was the principal investigator of the intervention study. She trained the nurses. AvD was interviewer for the ethical evaluation. She was not involved as part of the team of the intervention study. TvdW was as project leader involved in all aspects of the intervention study. GW was involved as an expert for the ethical evaluation. He was not involved in the trial. GE was part of the team of the intervention study as expert on shared decision-making.

with regard to the outcomes of the intervention study. All interviews were audiotaped and transcribed verbatim. Field notes were written during and after the interviews.

### Data analysis

The transcriptions of the interviews were imported in NVivo 2.0, which was used to structure the data. The interviews were analysed using directed content analysis.<sup>28</sup> Two researchers (AvD and MK), who were experienced in analysing qualitative data, coded the data independently, using a coding book. The analysis was partly deductive, as it started with a rough coding book based on the interview guide. The coding book developed during the coding process as more specific codes were derived from the data.

Coding discrepancies were discussed until consensus was reached. After the first, third and eighth interviews, the impressions gained from the interviews were discussed with GW and TvdW. Codes were sorted into categories based on the way they were related and linked. These categories were then used to cluster the data into five meaningful key themes. After analysing eight interviews, conceptual saturation was reached, as no new codes were identified. The remaining eight interviews were used to confirm the analysis and the key concepts that were found. Table 2 provides an overview of the authors' contribution regarding recruitment, data collection and data analysis.

### Results

The analysis resulted in five key themes, denoting crucial elements of patient involvement in CVRM: (1) clear answers and realistic advice received from the nurse, (2) being encouraged without being criticised, (3) being understood and helped to understand, (4) working together and (5) being motivated by the need to prove oneself to the nurse.

Patients' responses to the questions about risk communication, the patient decision aid and adapted motivational interviewing were short. Patients hardly reflected on these components of the intervention, and their answers quickly and spontaneously merged into stories about their attempts to achieve a healthier lifestyle and the importance of the practice nurse for these attempts. Although we made a distinction in the interviews and our coding book between the patients' own role, the role of the nurse and the significance of the consultation, the reported data could not be divided into these three topics. Patients' reports about the roles of patient and nurse

were intertwined, and the significance of the consultation seemed to have been determined by the cooperation between nurse and patient. Therefore, all the key themes related to the significance of the nurse to the patient. The key themes are described below. The patient identification number is given after each quote.

### *Clear answers and realistic advice*

Patients liked getting clear answers from the nurses to their questions about risk reduction and lifestyle change. Some patients reported that they already had decided what they wanted when they visited the nurse for the first time, and used the nurse to get information about ways to achieve their goals:

I told her I wanted to lose weight. I wanted more exercise. And so she actually recommended all these things to me. (Patient 3)

Advice about actions that are good and bad for their health was also appreciated by the patients:

I think she made things perfectly clear. She pointed them out to me and explained what would be better and what to concentrate on. It's good to know what to concentrate on. (Patient 7)

Patients reported that the nurses were able to explain well what they should do in various situations:

She told me precisely what to do. That I could break the rules a bit during the weekends, and what to do if I feel hungry during the week, indicating precisely what to take. (Patient 3)

According to patients, nurses helped them achieve their goals by means of practical and realistic advice. It was highly appreciated that the nurses took the patients' personal situation into account. At the nurse's advice, for instance, a patient decided to work on another risk factor first, and to make an attempt to quit smoking later because of a stressful situation at home. Another patient reported that the nurse had explained to him that although he had to try to improve his lifestyle, he should also enjoy himself, because other things in life are also important:

And the nurse also told me: you've got to live a little, don't you, you shouldn't become all depressed. You have to live a little. So that means I can have a fun weekend. I'm not going way over the top, but I do enjoy myself for a while. (Patient 11)

### *Encouragement*

Patients reported that a valuable aspect of visiting the nurse was that they were being encouraged and supported in their attempt to achieve lifestyle change. The nurse might compliment them by saying that they had done well, or that they were getting it right. Encouragements are important for patients to help them continue their attempts:

Well, she told me I'd done well! There's still room for improvement perhaps, but I can't go any faster than this. (Patient 4)

Some encouragement, yeah, someone taking an interest. That's very important to me. (Patient 12)

Patients also liked that there was someone to help them when they needed assistance. One patient reported that the practice nurse would not give up on her:

So she didn't tell me: OK, this is it, we're done. She still keeps in touch. And I'm very happy with that. (Patient 13)

Patients also reported that they had felt supported when nurses told them that they did not need to be afraid to do what they really wanted to do. This happened to a patient who was afraid to rejoin the sessions of her card playing club:

And she told me: just go ahead and do it. Try to relax a little. Because I was thinking: such a small room, lots of people, so hot. It frightened me a little. 'What if something happens to me?' But she explained it all to me and now I'm not afraid to go there. I was at first, yeah, I was scared. (Patient 7)

Patients perceived it as a major encouragement that they could tell their story when they failed in their attempts and that the nurse did not criticise them. In this approach, there is room to talk about patients' feelings and anxieties:

I must admit I always had this idea of: everyone tries it and if it doesn't work, you've failed and it means you're weak. But that's not the way she talks about it. She understands what I'm saying. Whether she agrees or not is a different story, of course. But it helps a lot that I'm not being criticized. (Patient 5)

### *Understanding patients and helping them understand*

Patients reported that nurses had understood them by being genuinely interested in them. Nurses took time to talk to patients about themes that were important to them, and patients felt at ease talking about these important issues:

She takes the time, she's always taken enough time to talk to me. I think you don't get as much time with a doctor. I never talked about these things with a doctor, but I felt very comfortable with her. (Patient 3)

According to the patients, the practice nurses knew about their personal situation, including problems in the work situation or a patients' wife being seriously ill. This was important to patients because they viewed their health as something that was related to other aspects of life:

Well, you see, it's not just a matter of having such and such a disease, you may also have other problems. And we can easily talk about those to the nurse. (Patient 11)

Nurses were also helpful in improving the patients' understanding of their own situation. One patient reported that the nurse had made her realise that there was a relation between her life events and the problems that she had with changing his lifestyle:

The nurse also told me this could be caused by the death of, . . . , [her son] the death, you know. And I didn't really feel like talking about that. I thought, that's my own business, that's personal. And then later I started to think, well yes, I have to admit, it was all very upsetting. I hadn't realised that at the time, not at all. So with hindsight, it was good. Someone had to tell me that, as I hadn't noticed myself. (Patient 4)

By helping patients to understand the relation between issues, nurses helped them to get a better grip on life and their preferred lifestyle. One patient mentioned that the general practitioner did not have enough time to do this.

### *Working together*

Many patients used words like 'together', 'we' or 'not alone' when reporting on the role of the practice nurses and the things they did to achieve lifestyle change. Although it is patients themselves who have to improve their lifestyle, they experienced it as a joint effort:



In principle, of course, I'm the one who has to do it, I know that, but I do feel it's a kind of support! You no longer feel that you're having to face it all on your own. And I think I really need that when it comes to giving up smoking. (Patient 5)

The choice of which risk factor to work on was also perceived as a joint effort by several patients. Patients reported that the nurse had asked them which topic they would like to discuss in the consultation, but that she had also tried to steer them in a particular direction:

We talked about what I'd read in the brochure [the patient decision aid]. So that was about smoking and eating fruit. And so she says: where shall we start? I said, let's start with the fruit [smiles ironically]. I mean, she does kind of steer me in the right direction. [...] In August, during the next consultation, the subject will be smoking again [smiles]. (Patient 5)

Other patients reported that the nurse had shown her preference for the risk factor to be reduced, although the patients would have the final say about what they wanted to do.

### *Proving oneself to the nurse*

Patients who had difficulty implementing lifestyle improvements reported that visiting the nurse was a motivation in itself to maintain healthy behaviour:

[Interviewer:] What is it that's given you the strength to give up unhealthy food now?

[Interviewee:] Well, I want to prove myself to her. We'd agreed that I'd give it [junkfood] up.

[Interviewer:] So it really helps you that someone ...

[Interviewee:] Yeah, I need an incentive. Because if no one had said anything to me, I might have done it. I might have stuck to the diet for a week, and then given up again and then done it again. But I was thinking: I'll show you. The next time I come to see you, then ... (Patient 3)

They wanted to prove themselves to the nurse and comply with the agreements they had made. The continuity of seeing the nurse motivated patients to work on their goals:

I'm not afraid of her [the practice nurse] [smiles] but ... yes, we made an agreement. I think that one has to take agreements seriously. (Patient 11)

## **Discussion and conclusion**

### *Discussion*

This study shows that patients who had been exposed to an intervention to stimulate patient involvement, involving risk communication, a patient decision aid and adapted motivational interviewing, appreciated the nurses' clear and realistic advice, their encouragement, their understanding of the patient's problems and the way they helped patients understand, and the cooperative approach, which reinforced their motivation and helped them to put their intentions into practice.

*Interpretation.* It appears that in trying to achieve a healthy lifestyle to reduce cardiovascular risk, patients need and use the support of a nurse to achieve their goals, for example, losing weight. When patients do not follow the nurse's advice, or in case of failure, they appreciate that the nurses are careful not to induce negative feelings, but rather look for results that are attainable, not focusing on the option providing the greatest

risk reduction, but on the most realistic one. Patients see the nurse as an incentive to prove that they can achieve the goals that they have agreed upon. When things are difficult, patients appreciate that the nurse shows empathy and understanding, and helps them understand the situation.

The patients in the trial were exposed to detailed probabilistic information on their cardiovascular risk, by means of a graphical risk communication tool, as well as a patient decision aid that they could study at home. In reflecting on the decision-making process, patients did not mention the facts and figures delivered by the tools, but emphasised their own efforts to achieve a healthier lifestyle and the support of the nurse. This seems to indicate that the joint effort to achieve lifestyle change is what really matters to patients. For patients, SDM has to do with working together to achieve risk reduction, with patients bringing themselves, with their circumstances, experiences and preferences, into the consultation, and the nurses contributing by offering supportive understanding and knowledge. Patients in primary care take arriving at a joint decision on CVRM with their nurse for granted. What really matters to patients is a joint effort which includes nurses' continuous support to achieve a healthier lifestyle.

*Comparison with the literature.* In the literature, information provision is seen as a condition for deliberation as part of SDM.<sup>4,29</sup> Studies suggest that presenting the individual 10-year risk of coronary heart disease is regarded as useful and motivating by patients,<sup>30</sup> but that professionals should be prepared to help patients understand the complex trade-offs between the factors influencing the decision, such as, for example, weighing beneficial effects against treatment burden of a risk-reducing intervention, to assist them in reaching a decision. Our study shows that patients in primary prevention are not interested so much in weighing the factors influencing the decision. Presenting data on cardiovascular risks is only a small element of CVRM, which is seen as hard work by patients, and for which they regard nurses' continuous encouragement, understanding, flexibility and commitment as important.

In the ethical literature, two approaches to autonomy can be distinguished<sup>31</sup> The first is autonomy in the ability to make one's own decisions, based on relevant information. The second is autonomy in the ability to shape one's own life, and develop patterns of behaviour which are meaningful in the context of a life-plan. Whereas the first approach to autonomy emphasises the importance of being free from external interference, the second presupposes that others can help a person to determine what is important in life and provide support in finding ways of dealing with difficulties in life, supported by others. An example of the second approach is the concept of relational autonomy, which emphasises that a person develops an identity through relationships with others. The current notion of patient autonomy in CVRM, which focuses on information on health risks, does not do justice to the experience of patients that they need the nurse's support in managing challenges and difficulties they encounter in trying to adopt a healthy lifestyle. The concept of relational autonomy seems to be more adequate for CVRM. This implies that nurses should not focus on providing information on risks, but on supporting patients in finding out what health behaviour is appropriate and feasible, and fostering their ability to shape their lives in a meaningful way.

Our finding that patients experienced CVRM as a joint effort is in line with the ethic of care. Tronto<sup>32</sup> describes care as a practice based on mutual involvement. Care is not a one-sided action, but requires a relationship of commitment and shared responsibilities. This comes to the fore in our key theme of 'working together'. Care requires attentiveness and support, aspects that are present in our key themes of 'encouragement' and 'understanding the patient'. Care should also be responsive, which implies that it is adjusted if needs are not met, an element which can be seen in our key theme 'clear and realistic advice'.

Our findings also fit in with the concept of 'communicative action' developed by Habermas.<sup>33</sup> According to Habermas,<sup>34</sup> in 'communicative action', actions are coordinated through an orientation at reaching understanding. Communicative actions are linked to what he calls 'the life-world', that is, the world viewed from the perspective of the participant of an interaction. This world is structured and reproduced through

verbal language, and comprises culture, the social world and personality. This is in line with our finding that patients perceive health as something that is related to all aspects of daily life, and that they need the support of nurses to understand these relations, and act according to the circumstances. Habermas' theory of communicative action emphasises the importance of deliberation. This is also present in the deliberative model of Emanuel and Emanuel.<sup>35</sup> According to the deliberative model, the aim of the nurse–patient relationship is to help the patient determine and choose the best health-related values that can be realised in the clinical and home situation. The role of the nurse is that of a friend or teacher. The nurse has to help articulate and persuade the patient of the most admirable values as well as inform the patient and implement the patient's selected intervention. In the model, autonomy is regarded as self-development, in line with the second approach to autonomy described above. The deliberative model can be seen in the example of the nurse recommending making realistic plans for lifestyle improvement and not setting the goals too high, taking into account the patient's vulnerability and helping the patient to fit health behaviour into her life-plan.

*Strengths and limitations.* Our study examined the experiences of patients in detail. The data were gathered by an experienced interviewer. The data were analysed by several researchers, including non-members of the team of the intervention study (GW and AvD).

For this study, we wanted to interview patients who had been exposed to a well-implemented intervention to promote patient involvement. To this end, we asked five nurses who had implemented the patient involvement intervention in the way it was intended, to invite patients for an interview. The method of recruitment is likely to have led to bias in patient choice, as nurses could have invited patients who had done well and were prepared for the interviews, so that we have heard success stories about the nurses. Other patients of the same nurses, or patients of other, less well-performing nurses may have had different experiences regarding SDM and autonomy in the context of CVRM. Yet, our study did not aim to evaluate the level of competence of nurses; it focused on patient experiences with the intervention in accordance with the standards. As such, it reveals that patients appreciate the attention and support of nurses and regard SDM as joint work, which was not envisaged in the project.

Our study was limited to patients' experiences with risk communication and SDM, and their views on the role of the nurse. It does not provide information about patients' actual behaviour. Our findings suggest that merely risk communication tools and SDM – although these may be important conditional factors – are only of limited value in actual lifestyle changes that lead to improvements in patients' health. Patients particularly valued the encouraging and continuous support of the nurse in the ups and downs of their life. However, we do not know whether a supportive role of the nurse really makes a difference regarding improvements in patients' health status. Patients talked about healthy lifestyle changes, but their perceptions about their lifestyle were possibly more positive than the objective improvements in health.<sup>36</sup>

## Conclusion

Patients experienced nurses' understanding and encouragement as crucial elements of a nurse-led intervention for involving patients in CVRM, including risk communication, a patient decision aid and adapted motivational interviewing. For patients, being involved in CVRM is seen as a joint effort aimed at a healthier lifestyle. Nurses should be trained to perform SDM not only as arriving at a joint decision based on adequate information about risks but also as supporting the patient in shaping his or her life, and working with the patient to achieve the goals in a realistic way. This requires continuity of consultations, support and understanding, helping the patient to set achievable goals and act in line with them.

## Funding

This work was supported by the Netherlands Organisation for Health Research and Development (project number 945-04-055) and Maastricht University.

## Conflict of interest

None declared.

## References

1. Perk J, De Backer G, Gohlke H, et al. European guidelines on cardiovascular disease prevention in clinical practice (version 2012). The Fifth Joint Task Force of the European Society of Cardiology and Other Societies on Cardiovascular Disease Prevention in Clinical Practice. *Eur Heart J* 2012; 33: 1635–1701.
2. World Health Organization. *Adherence to long-term therapies. Evidence for action*. Geneva: World Health Organization, 2003.
3. Burke LE, Dunbar-Jacob JM and Hill MN. Compliance with cardiovascular disease prevention strategies: a review of the research. *Ann Behav Med* 1997; 19: 239–263.
4. Charles C, Gafni A and Whelan T. Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). *Soc Sci Med* 1997; 44: 681–692.
5. Towle A, Godolphin W, Grams G, et al. Putting informed and shared decision making into practice. *Health Expect* 2006; 9: 321–332.
6. Elwyn G, Laitner S, Coulter A, et al. Implementing shared decision making in the NHS. *BMJ* 2010; 341: c5146.
7. Edwards M, Davies M and Edwards A. What are the external influences on information exchange and shared decision-making in healthcare consultations: a meta-synthesis of the literature. *Patient Educ Couns* 2009; 75: 37–52.
8. Gravel K, Legare F and Graham ID. Barriers and facilitators to implementing shared decision-making in clinical practice: a systematic review of health professionals' perceptions. *Implement Sci* 2006; 1: 16.
9. Koelewijn-van Loon MS, van Steenkiste B, Ronda G, et al. Improving patient adherence to lifestyle advice (IMPALA): a cluster-randomised controlled trial on the implementation of a nurse-led intervention for cardiovascular risk management in primary care (protocol). *BMC Health Serv Res* 2008; 8: 9.
10. Laurant M, Reeves D, Hermens R, et al. Substitution of doctors by nurses in primary care. *Cochrane Database Syst Rev* 2005; CD001271.
11. Van Steenkiste B, van der Weijden TM, Stoffers JH, et al. Patients' responsiveness to a decision support tool for primary prevention of cardiovascular diseases in primary care. *Patient Educ Couns* 2008; 72: 63–70.
12. NHG. *M84 NHG-Standaard Cardiovasculair Risicomanagement* [Dutch guideline for Cardiovascular Risk Management]. Houten: Bohn Stafleu van Loghum 2006, 54pp.
13. Stevens RJ, Kothari V, Adler AI, et al. The UKPDS risk engine: a model for the risk of coronary heart disease in type II diabetes (UKPDS 56). *Clin Sci (Lond)* 2001; 101: 671–679.
14. Edwards A, Elwyn G, Covey J, et al. Presenting risk information – a review of the effects of 'framing' and other manipulations on patient outcomes. *J Health Commun* 2001; 6: 61–82.
15. Timmermans D, Molewijk B, Stiggelbout A, et al. Different formats for communicating surgical risks to patients and the effect on choice of treatment. *Patient Educ Couns* 2004; 54: 255–263.
16. van Steenkiste B, van der Weijden T, Stoffers HE, et al. Improving cardiovascular risk management: a randomized, controlled trial on the effect of a decision support tool for patients and physicians. *Eur J Cardiovasc Prev Rehabil* 2007; 14: 44–50.
17. Rollnick S and Miller WR. What is motivational interviewing? *Behav Cogn Psychother* 1995; 23: 325–334.
18. Rollnick S, Mason P and Butler C. *Health behavior change. A guide for practitioners*. London: Churchill Livingstone, 1999, 225pp.

19. Rubak S, Sandbaek A, Lauritzen T, et al. Motivational interviewing: a systematic review and meta-analysis. *Br J Gen Pract* 2005; 55: 305–312.
20. Koelewijn-van Loon MS, van der Weijden T, van Steenkiste B, et al. Involving patients in cardiovascular risk management with nurse-led clinics: a cluster randomized controlled trial. *CMAJ* 2009; 181: E267–E274.
21. Koelewijn-van Loon MS, van der Weijden T, Ronda G, et al. Improving lifestyle and risk perception through patient involvement in nurse-led cardiovascular risk management: a cluster-randomized controlled trial in primary care. *Prev Med* 2010; 50: 35–44.
22. Elwyn G, Frosch D and Rollnick S. Dual equipoise shared decision making: definitions for decision and behaviour support interventions. *Implement Sci* 2009; 4: 75.
23. Keszthelyi S and Blasszauer B. Challenging non-compliance. *J Med Ethics* 2003; 29: 257–259.
24. Conrad P. The noncompliant patient in search of autonomy. *Hastings Cent Rep* 1987; 17: 15–17.
25. Breitsameter C. Medical decision-making and communication of risks: an ethical perspective. *J Med Ethics* 2010; 36: 349–352.
26. Conroy RM, Pyorala K, Fitzgerald AP, et al. Estimation of ten-year risk of fatal cardiovascular disease in Europe: the SCORE project. *Eur Heart J* 2003; 24: 987–1003.
27. Widdershoven GAM and Weijts LBM. Diagnostic styles in clinical interaction. In: Fulford KWM and Dickenson D (eds) *Blackwell reader in healthcare ethics and human values*. Oxford: Blackwell's, 2002, pp. 171–176
28. Hsieh HF and Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res.* 2005; 15: 1277–1288.
29. Elwyn G, Edwards A, Kinnersley P, et al. Shared decision making and the concept of equipoise: the competences of involving patients in healthcare choices. *Br J Gen Pract* 2000; 50: 892–899.
30. Sheridan SL, Behrend L, Vu MB, et al. Individuals' responses to global CHD risk: a focus group study. *Patient Educ Couns* 2009; 76: 233–239.
31. Widdershoven GAM and Abma TA. Autonomy, dialogue, and practical rationality. In: Radoilska L (eds) *Autonomy and mental disorder*. Oxford: Oxford University Press, 2012, pp. 217–232.
32. Tronto JC. *Moral boundaries: a political argument for an ethic of care*. New York/London: Routledge, 1993.
33. Habermas J. *The theory of communicative action, volume 1: reason and the rationalization of society*. Cambridge: Polity Press, 1986, 465pp.
34. Habermas J. *The theory of communicative action, volume 2: lifeworld and system – a critique of functionalist reason*. Cambridge: Polity Press, 1987, 457pp.
35. Emanuel EJ and Emanuel LL. Four models of the physician–patient relationship. *JAMA* 1992; 267: 2221–2226.
36. Jansink R, Braspenning J, Keizer E, et al. Misperception of patients with type 2 diabetes about diet and physical activity, and its effects on readiness to change. *J Diabetes* 2012; 4: 417–423.

## Appendix I

### Interview questions

#### OPENING

*This interview is about your experiences, expectations and preferences regarding the consultations concerning your risk on cardiovascular diseases. I would like to start with your experiences. Let us look back at the consultations. You visited the practice nurse for the assessment of your cardiovascular risk.*

1. Could you please tell me, how was the consultation going?

*You visited the practice nurse for a second time to think and discuss further about risk reduction opportunities.*

2. Could you please tell me more about that consultation? How was it going?

So, you have heard that you have a (high/low/percentage) cardiovascular risk. And in the second consultation, you discussed mainly ... [topic] (short summary)

- Who contributed to this topic?
- Were you engaged in/doing something with/thinking about this topic before?
- Did it give you new insights or ideas? If yes, which ones?
- What are you doing with it now? How does it affect your life now?

#### EXPECTATIONS

3. Could you please tell me more about the expectations you had beforehand about the consultation?

- Why did you go to the consultations?
- What was most important for you regarding the consultations?
- What did you expect that would be discussed?
- Did you have high hopes for the consultation or not at all? Why?
- How did you prepare yourself for the consultations?
- What did you expect your contribution could be to the discussion?

#### EXPERIENCES

So, you expected ... (short summary)

4. How did your expectations turn out?

- Who determined the topic of discussion?
- Could you please tell me more about the possibility to discuss your preferences and opinion?
- How did you experience the role of the practice nurse?
- How did you experience the discussion on possible tips and tools for risk reduction?
- What did you not expect?

**RISK COMMUNICATION:** *In the first consultation, the practice nurse explained your risk on cardiovascular diseases. She used the so-called risk-chart for this explanation.*

5. Could you please tell me what she has told you about your risk?

- How do you see your risk of cardiovascular diseases? Did your view on this change? How did you look at your risk before the consultations?
- What was your opinion about being informed about your risk? What does that mean to you? Does it have any influence on your life? Is there a difference between before and after the consultations?
- How did you experience the way the practice nurse explained your risk?

**DECISION MAKING:** *At the end of the first consultation, you received a brochure with information, to take with you.*

6. What have you done with this brochure?

- When it was read: what do you remember about the brochure?
- What was the significance of this brochure for you? For your thinking and acting?

→ What was the significance of the discussion about this information for you? In addition to the written information?

7. Did you arrive at concrete agreements about reduction of your risk, for example, about strategies or goals? If yes: Could you please tell me more about that?

→ What is your opinion about this/these appointment(s)?

→ Could you tell me what you are doing with these appointments? Why or why not?

→ Who made these appointments?

→ How receptive was the practice nurse to your ideas?

→ How did you consider the input of the practice nurse?

#### PREFERENCES

*We talked about how you have experienced the consultations.*

8. What is important for you in a consultation about your cardiovascular risk ...

→ ... regarding your own role?

→ ... regarding the role of the practice nurse?

→ According to your opinion: when is a consultation successful?

#### CLOSING OF THE INTERVIEW

9. Do you have something to add to this interview about the consultations?

→ ... were there any elements missing in the consultations?

→ ... things you would like to be changed?