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Patient coaching in secondary care

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Original Research Article

Patient coaching in secondary care: healthcare professionals' views on target group, intervention and coach profile

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Abstract

Background: Not all patients are able to communicate effectively during consultations with medical specialists. Patient coaching has shown to be effective for enhancing communication.

Objective: We aimed to get healthcare professionals' views on target groups for patient coaching, on supportive elements in patient coaching and on the necessary qualifications and profile of a patient coach, to further our knowledge on the concept of patient coaching as supportive intervention for patients in consultations with medical specialists.

Methods: We chose a qualitative research design and interviewed 18 healthcare professionals (six medical specialists, four family physicians, four community nurses and four nurse specialists/physician assistants) and analysed the verbatim transcripts using Qualitative Analysis Guide of Leuven. After a short introduction of the global concept of patient coaching and presentation of patients' perceived barriers, two interviewers structured the interview around three research questions: which patients could benefit from a patient coach, what should such a coach do and who could act like such a coach?

Results: Participants describe patients who could benefit from patient coaching as generally vulnerable (e.g. older age, insufficiently accompanied, lower socioeconomic status, co-morbidity and cognitive problems) but also patients who are situationally vulnerable (e.g. elicited by bad news). Patient coaching should comprise emotional and instrumental support, aiming at reducing stress and improving the processing of medical information. Patient coaching should start from the

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patient's home and include preparing questions, navigating to and in the hospital, recording information during the consultation, checking understanding and recalling information. Patient coaches should have at least basic medical knowledge and a higher education.

Conclusion: Healthcare professionals believe that patient coaching by a trained professional with medical knowledge could be beneficial to patients who are stressed when visiting a medical specialist. Future research should involve the views of patients on patient coaching, focus on investigating to what extent patient coaching is able to reduce stress and support a patient in processing medical information and the preferred patient coach's profile.

Key words: communication, patient coaching, healthcare professionals, target group, patient coach profile, interviews

Introduction

Although effective communication [1] and shared decision-making [2] are generally acknowledged to be important for the provision of high-quality specialist care, many patients lack the skills to participate fully in their own care. Many of them encounter communication barriers [3–5]. Patient coaching might support patients in overcoming these barriers [6] and is desired by one in six patients consulting a medical specialist, but it is scarcely investigated [7].

In a representative sample of the non-institutionalized chronically ill population in the Netherlands, one in every six patients reported interest in support from a patient coach when visiting a medical specialist [3]. Such interest appears to be related to specific communication barriers, such as feeling tense or being uncertain about one's own understanding and believing that a certain topic is not part of a healthcare provider's task. Other patient-related factors for interest in a patient coach are older age, limited health literacy skills and a lower level of perceived self-efficacy [7]. Supporting patients with a possible need for a patient coach requires their identification. How healthcare professionals identify patients who could benefit from a coach is unknown.

A patient coach is described as a companion who supports a patient in preparing for consultations with a medical specialist, accompanies the patient during this consultation and evaluates the consultation afterwards [3]. Patient coaching has been investigated in only a few high-quality studies. Most interventions involved a single individual session before a consultation with a medical specialist [8-12]. Because the investigated coaching interventions varied in frequency and content, the key components of an effective patient coaching intervention are still unknown [6]. These studies showed that patient coaching improves the communication with a medical specialist, not only during the consultation but also in the long term. In the present study, we explored healthcare professionals' views on what patient coaching should comprise, and which patients could benefit from such coaching, to ensure effective communication with a medical specialist. In addition, to further our knowledge on patient coaching, information on the coach's background and training is essential. However, the currently available literature on patient coaching offers very limited information on this issue [6]. We therefore also explored healthcare professionals' opinions on the desired qualifications and profile of a patient coach.

The aim of this study was to obtain an in-depth understanding of healthcare professionals' views on a coaching intervention for

patients with a chronic disease in secondary care. Specifically, we asked the following questions:

- (i) Which patients could benefit from a patient coach?
- (ii) What kind of support should a patient coach provide?
- (iii) Who would be best qualified to act as a patient coach?

Methods

Study design

Given the exploratory nature of our research questions, a qualitative study design was chosen. Study design and results are reported in compliance with the Standards for Reporting Qualitative Research [13].

Sampling

We purposively sampled medical specialists, family physicians, nurse specialists and community nurses (CNs) [3]. Medical specialists were invited to participate through the personal network of one of the authors who is a senior medical specialist himself (PB). Nurse specialists were recruited as suggested by the participating medical specialists. In primary care, family physicians and CNs were recruited through the network of the researchers (IA and CS). All approached healthcare professionals agreed to participate.

Setting

Participants were invited for a single interview by an informative email. If they were interested, the researcher explained the aim of the study by telephone and made an appointment for the interview at a date, time and location convenient to the participant. The medical specialists and nurse specialists were interviewed at the clinic, the family practitioners were interviewed at the university college, the researcher's home or their home and the CNs at their office. Two researchers (IA, female and RK, male) conducted individual in-depth semi-structured interviews. None of the participants had previously worked in patient care with the two researchers.

The aim was to interview at least four healthcare professionals from each of the abovementioned professions.

Ethics

All participating healthcare professionals provided written informed consent. Participants waived reading their transcript or manuscript

Table 1 Topic list

Describe a patient and his/her situation

Describe as vividly as possible: what diagnosis this patient has, his/her age, sex, education, living situation, being accompanied during the consultation or not, etc.

- Do you think this is a general problem of this patient or is it dependent on the type of consultation?
- Do differences in the way patients communicate and participate during the consultation affect your perception of the effectiveness of the consultation?
- What are your experiences as a care professional, which patient-related barriers do you perceive?
- How did you (try to) resolve these so far?
- Why do you think it is important to support this patient with a coach?

How could a coach support this patient?

Save talking about the 'Who' section (for profile) until the end of the interview

- Why this patient?
- What kind of support does this person needs, what would the support have to look like?
- Where should this coaching take place?
- At which moment should this coaching take place and how often?
- What should be emphasized in the coaching (practical, explanatory, emotional, a combination or something else)?
- Thinking about all of this: what is most important? And why?

Who could offer such kind of support? (creating a coach profile) Think about:

• What kind of person is this coach? (Keep thinking of personal support. Try to make this as clear as possible, resulting in a profile.)

before publication. This study was exempt from medical ethical review under Dutch law.

Data collection

Based on previous studies [3, 7], a discussion within the research group and a pilot interview with a medical specialist, an interview topic list (Table 1) was developed.

Responses from interviews were used to update the topic list for subsequent interviews. All interviews were conducted between 1 November and 15 December 2017. Interviews were continued until no further themes emerged from ongoing analyses, and saturation was reached. Field notes were made after interviews and discussed between researchers.

Each interview started by presenting an oral description of the concept of a patient coach, based on the results of our systematic review [6], and a previous study about patients' interest in a patient coach when visiting a medical specialist. We then asked the healthcare professional to picture an actual patient by asking 'Can you think of a patient who needs more communication support than is available right now, for example someone you think would like to be accompanied when visiting a medical specialist?' The case description was used as a basis to explore potential communication barriers that could be overcome by patient coaching. If needed to facilitate discussion, examples of barriers were given from a 17 barriers list resulting from a previous study (e.g. 'feeling tense' and 'remembering the subject only afterwards') (Supplementary Appendix 1) [7].

Data analysis

Interviews were audio-recorded, transcribed verbatim by an external agency and analysed by four researchers using content analysis (IA, LG, AEMV and CS) [14]. To guide the analysis process, we used Qualitative Analysis Guide of Leuven (QUAGOL) [15]. QUAGOL is a comprehensive and systematic method, characterized by an iterative process and backward-forward movement between stages of the analysis. In the first part, the coding process is prepared. The second part comprises the actual coding process.

The first part started by writing a structured extract of every transcript (Supplementary Appendix 2), to capture general themes related to our topic list and study aim, and other themes emerging from the interviews. Subsequently, we wrote a descriptive summary derived from reading and re-reading four interview transcripts (one from each of the disciplines). These descriptive summaries and storylines were used to develop a conceptual coding scheme by dialogue and consensus between two researchers (IMRA and LG). The conceptual coding scheme was discussed between researchers and adapted after applying it to four interviews (I.A, CS and AEMV) [16]. The final code scheme was discussed and agreed with the whole research team.

In the second part, the first researcher coded the interviews with this thematic coding scheme, using qualitative data analysis software (Atlas-ti Version 8).

Reflexivity

It is inevitable that the researcher influences the research process, and, therefore, reflexivity is essential [17]. The first researcher (IA) is familiar with the practice of medical specialists and family physicians after >20-year experience as a pharmaceutical sales representative. This familiarity guided the decision to let her interview the physicians. She is also familiar with patient coaching, having worked as a patient coach herself. This experience might have affected her communication during the interviews and her interpretation of transcript data assuming patient coaching to be effective. RK is a teacher of nurses at the level of vocational training. This guided the decision to let him interview the nurses. The other researchers added a broader perspective to the research setting (PhD dementia care [LG, female], MSc life sciences and PhD student care for older people [AEMV, female], psychologist [SD, female], geronto-psychologist [CS, female] and medical specialist [PB, male]) to limit researcher bias in the preparation and the analysis of the study.

Results

Participants

We interviewed 18 healthcare professionals: six medical specialists (MSs), four family physicians (FPs), four nurse practitioners/physician assistants (NPs) and four CNs, with 7-27 years of clinical experience. Two FPs had been diagnosed with cancer. The average interview duration was 60 minutes.

Themes and categories

Following the research questions, the final code scheme covered the following themes [1]: patient characteristics and his/her situation [2], coach activities and behaviour and [3] coach profile. One additional theme was identified [4]: what should patient coaching aim at (Table 2).

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Table 2 Themes, categories and codes

| Themes | Categories | Codes |
|---|-----------------------|---|
| 1. Patient | | |
| | Characteristics | Age, sex, culture, language, education, attitude, behaviour, personality, cognitive ability (related to the consultation), cognitive ability (generic), psychiatric illness, communication skills, health literacy, motivation for self-management and avoiding health care |
| | Situation | Context and kind of consultation |
| 2. Patient coaching | | |
| Activities | Before consultation | Preparation, accompany to and in hospital |
| | During consultation | Listening, recording and managing conversation and question asking |
| | After consultation | Information recall, explanation, psychological support and inform and involve network |
| Behaviour/attitude 3. Patient coach profile | During consultation | Consciousness of role/position and professional skills |
| • | Knowledge | Medical, healthcare organization and psychological |
| | Skills | Communication, coaching and observational skills |
| | Educational level | Education |
| | General | Motivation, age and personal experience |
| | Current position | Volunteer, retired healthcare professional, etc. |
| | Trainability | Willing and able to learn coaching skills |
| 4. Aim of patient coaching | | |
| | Support patient | Enable releasing patient's anxiety, create clarity and advocacy, prevent complications and prevent official complaints and empowering |
| | Support professionals | Insight into network and professional information exchange |

The results are described by what the participants disclosed in the interviews in response to our research questions. A schematic representation of results is given in Figure 1.

Example quotations are shown in Table 3.

Patient characteristics

The following characteristics of patients who might benefit were mentioned: inability to process medical information, to determine which information is relevant to share with the medical specialist and to actually share it in the consultation.

Generally vulnerable patients

Most participants initially thought of patients who are generally vulnerable, like elderly people, and people living alone, with a small social network, who are insufficiently accompanied, avoid healthcare, with a lower socioeconomic status, with complex health problems (e.g. co-morbidity) and with cognitive problems.

According to the participants, these vulnerable patients are only partly capable of processing medical information to make an informed treatment decision.

Situationally vulnerable patients

When we asked participants to reflect on the impact of various factors affecting the care process—such as the level of health literacy, the point of time in the care trajectory (diagnosis, treatment and control), the type of care given (curative and palliative) and a patient's coping style—participants indicated that particularly vulnerability is an important characteristic of patients with a probable need for a patient coach. This vulnerability can be not only a continuous characteristic, as described above, but also situational: caused by stressful circumstances.

The experiences of two family physicians who had been diagnosed with cancer themselves illustrate how they, even as physicians, had difficulties to remember, understand and process all information as patients.

Kind of support

According to the participants, patient coaching should relieve a patient by reducing consultation-related stress and enabling processing medical information.

Stress reduction and processing information

A patient coach can contribute to stress reduction by providing support in preparing for the consultation at the patient's home (writing down questions, naming concerns and expectations), navigating to and in the hospital, being present during the consultation to support question asking and expressing concerns and assuring that information is recalled and discussed afterwards.

Participants think that patient coaches can support patients process and comprehend medical information, by facilitating recall (being 'extra ears', making notes or audio-record), checking understanding, asking for clarification of information from the medical specialist or clarifying it themselves, during and after the consultation to ensure informed consent.

When a patient does not reveal his questions and concerns in the consultation, a coach should create the opportunity to do so, by helping the patient to remember, by encouraging the patient or advocating on behalf of the patient or family.

Duration of patient coaching

Participants indicated that the length for support differs per person, being dependent on the patient's ability to handle stress and process medical information effectively. They believe that most patients can learn how to do that. When patients are *generally* vulnerable, they might need support over a longer period of time.

Patient coach profile

Knowledge

A patient coach should have basic medical knowledge and knowledge on how care processes are organized in the hospital, to be able to prepare relevant questions and manage expectations.

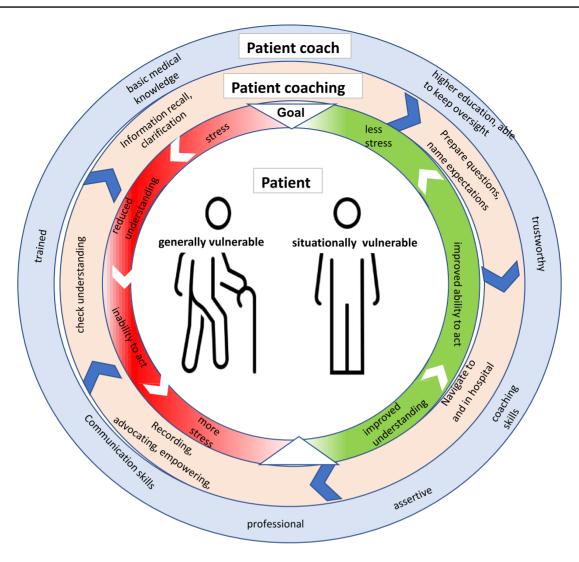


Figure 1 Patient, patient coaching goal, supportive elements and process and coach qualifications.

A patient coach should be able to translate and clarify the proposed treatment options to the patient's current medical and social context, attuned to his possibilities and restrictions.

Skills

A patient coach should have the skills to personalize support, attuned to the patient's possibilities to communicate effectively within the consultation. This requires adequately observing, listening and interpreting a patient's stress level and ability to process information and acting accordingly.

Subsequently, a patient coach needs to be able to estimate when the support can be adapted or ended, because a patient has learned to communicate effectively within the consultation.

Coaches need to be very well-trained in communication skills (e.g. listening, interpreting verbal and non-verbal cues and verbal communication with provider), according to the participants.

Attitude and behaviour

Participants can imagine that coaches should have a professional attitude towards the patient and be able to strike a good balance between distance and involvement.

A coach should also be able to build trust, by being clear about confidentiality and being easily available, even for a longer period of time and for multiple consultations (continuity).

Professional or volunteer

The participants proposed different professionals with at least higher vocational education who would qualify as a patient coach, including nurses, medical secretaries, welfare workers and family physicians.

Hospital navigation volunteers (currently available in most hospitals in the Netherlands) are less qualified according to the participants, because they tend to translate the patient's situation to their own situation, which is not appropriate. They might have a role in transportation, navigating in the hospital, recording the consultation and chatting afterwards. To provide more profound support, they need additional training.

Discussion

Statement of principal findings

According to the healthcare professionals in this study, specifically,

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| Table 3 Results: themes and quotations | otations | |
|---|---|---|
| Theme | Results | Quotations |
| 1. Patient characteristics 2. Patient coaching, kind of | Generally vulnerable patients Situationally vulnerable patients | 'A woman, low socioeconomic status, with a lot of health problems. Diabetes mellitus, psychiatric illness, social issues, financial issues. Very kind but needs a lot of care.' (FP03) 'I had a man, somewhat cognitively limited. Only went to primary school, and because of alcohol he is having even more cognitive problems (). Has no informal caregivers' (CN08) 'For example, I had a man, an elderly man, somewhere in his late eighties, and he lived with his brother on a farm (). This is also a man who, since his youth, has been slightly retarded, () he was admitted to the hospital [because of a hip injury] () and quite often you need to exchange medical () information with him. He does not understand everything (). You sense that his brother is very interested in it, but he doesn't understand it exactly either.' (NP12) 'I'm thinking of a hypothetical patient, who heard he has cancer (). Because they are paralyzed by the bad news, but they also have to undergo examinations (). People come here and they can, () really loose it and feel lost. And feel overwhelmed. Feeling small: (MS06) 'Man is as intelligent as his emotions allow him. So when someone is high in his emotions, for a while he just is not able to sort it all out. So emotions blur your thinking for a while. And you see that very often.' (NP17) 'I've experienced same-day testing [for cancer], and then you are a medical professional, you know how it works (). It's more about the fact that you can't handle it at that moment. That you're not able to ask questions immediately or to understand immediately what is being told, or to oversee what you're facing (). Well educated, poorly educated. When you are very scared, you aren't able to listen and make considerations anymore?' (FP03) |
| support and aim | Stress reduction and processing information | 'I think it is desirable if they [the coach and the patient] have a conversation at home, about: what do you expect of the medical specialist and what do you want to know [] and also be less questions, less haziness too. So it will give people clearer view on what has been discussed and, so there will also be less questions, less haziness too. So it will give people more peace of mind too, actually, less stress, before and after.' (FP10) 'Then, they're often worriers. Having walked all these hospital hallways, indeed, arrive here already very tired. I think people would be very pleased if they had patient coaching starting from their homes: look, you can park over here, I'll walk with you and I'll explain everything again Sure, I presume: (MS06) 'It's all about the coach having a pair of extra ears. And able to take notes, discuss them with the client or patient afterwards. () that someone just brings his eyes and ears. Because in the end every patient needs to be informed by his doctor in such a way that he knows what he's up against ().' (NP17) 'When a patient shuts down or loses track of what is being discussed and At that moment, indeed, the coach can step in or support and easy: at home you said you wanted to know about this, () is everything clear to you? To have a bit of a chaching role, 'FP09) |
| | Duration of patient coaching | I think there is a large group of in particular vulnerable elderly, who really have a need for, let's say a coach, not just for a short period, but really for an extended period of time (). (NP12) 'And one person will be quicker in capturing this than another. I don't think there should be a maximum or so, like, you only get a coach for five times, no, it shouldn't be like that. More that it is a bit dependent on the patient (). (FP10) Continued. |

| Table 3 (Continued) | | |
|--------------------------|---------------------------|---|
| Theme | Results | Quotations |
| 3. Patient coach profile | Knowledge | "He [the coach] must have knowledge of the pathology, because otherwise, in my experience, people who come along as companion do not understand what it is all about()? (MS14) '() they the coaches should only discuss the options, and just what has been discussed. Repeating that. (), when |
| | Skills | people really want another advice, they're referred back to the medical specialist or the family physician.' (FP10) 'To be able to interpret medical information and translate it to consequences for patients, firstly coaches need to be sensible: it is sensible to know how to listen and how to interpret and observe what -' (FP02) 'When people become increasingly aware, like this is how I can prepare it and that people are able to grow in that. At a certain point it will no longer be needed. That the patient can be trained in this, (FP10) |
| | Attitude and behaviour | 'I do think that these persons [potential coaches] can be trained ()- that is a quite difficult education, because they have to be very strong in communication.' (MS14) '() it needs to be a resolute personality. 'Els' [the coach], must be confident. And have a professional attitude, also towards the patient. Not just comforting, she remains a coach to ensure good communication and not a friend or something ()' (MS04) |
| | Trust | So you're not actively asking the questions yourself to the doctor. You're asking the patient (). Indeed, you're really a kind of manager of that conversation.' (FP03) 'Indeed that he is assertive and dares to speak up for someone. (CN11)' 'But also that there is continuity. I mean, preferably the same person, because that builds trust and provides continuity.' (FP10) 'This lady's coach ['Els'] has already visited her twice at home to make an inventory of her questions. And three months |
| | Professional or volunteer | ago, before the operation, she was also present, she's still the same coach. I think that's very important. So 'Els' starts to become a bit of a trusted person, like, well, 'Els' knows about that, and oh, I need to remember that for 'Els'. Because, she'll be here next week, so we can include it in the consultation with the specialist. (MS04) 'You need to be able to keep overview And then, to be able to stand above the conversation a little bit, even when the conversation is getting difficult. If the specialist and the patient run into a sort of argument, it's nice if someone has a conversation is getting difficult. |
| | | when then? (FP03) 'When they [volunteers] accompany patient to the front door, that's a good idea. When patients are accompanied downstairs, that's also a very good idea. But if there is a question along the way, like the doctor said I have COPDinformation needs to be a bit unambiguous. Then they will probably go like,, but my neighbour has COPD and she's not like you.' (MS07) |

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generally or situationally vulnerable patients may benefit from patient coaching. Patient coaching should aim at supporting a patient by reducing stress and by processing information, preferably by empowering patients instead of advocating for them. When patients continue to be unable to communicate effectively during consultations with medical specialists, coaching should continue. Patient coaching should be a cyclic process with multiple contacts, attuned to a patient's need, with the same coach to ensure continuity and trust. Patient coaching comprises preparation of the consultation at home, navigation to and in the hospital, recording the consultation, facilitating question asking and expressing concerns, checking understanding, providing clarification and stimulating information recall. A patient coach should preferably be a professional or trained volunteer with a higher educational level, basic medical knowledge and sufficient coaching and communication skills to act in a patient's best interest.

Perhaps the most striking finding of our study is that participants feel that patients with situational (i.e. temporary) vulnerability may also benefit from support from a patient coach when consulting a medical specialist. This view is consistent with the results of our previous study on the views of patients with and without an interest in a patient coach when visiting a medical specialist. Three specific communication barriers distinguished patients with interest in a patient coach: feeling tense, little confidence in one's own understanding or thinking that certain subjects do not belong to a particular healthcare professional's field of expertise. These barriers did not relate to educational level, health literacy level or age [7]. Patients who feel tense have difficulties understanding and processing information [18, 19]. Providing emotional and instrumental support before, during and after the consultation by a trusted, professional patient coach might reduce stress and thus enable a vulnerable patient to communicate effectively in the (next) consultation. Healthcare professionals may suggest the use of a patient coach to these patients.

Strengths and limitations

Our current study is unique in addressing the views of healthcare professionals on a new personal intervention to support patients to fill a potential gap in communicating with medical specialists. Since we explored the concept of a hypothetical intervention, participants might have imagined different kinds of patient coaches. This might be a limitation of this study, but it also has its assets by leaving room for improvement of the concept by adding new elements. This study only investigated the views of healthcare professionals; patients' perspectives will be assessed in a follow-up study. Another limitation is that we interviewed small groups of healthcare professionals in one region of the Netherlands, which limits the generalizability of our results.

Interpretation within the context of the wider literature

Only a few studies relate the goals of patient coaching to the training or profile of a patient coach. The most investigated coaching intervention is Consultation Planning, Recording and Summarizing, in which the patient coach is called 'Patient Navigator'. As costs were a barrier for implementation, 'coaches' in these studies were unpaid (future) professionals: trained post-baccalaureate and pre-medical interns [20–26]. This type of coaching has also been offered and evaluated in the Netherlands ('Zorgbuddy' and 'Medgezel'). These coaches, however, differ from our patient coach concept, because their goal is twofold: supporting the patient and teaching future physicians key communication competencies [25, 26]. It is yet to be determined if

the profile and training of these medical students sufficiently match the desired profile and outcomes of patient coaching.

Implications for policy, practice and research

Despite the documented beneficial effect of patient coaching on effective patient–provider communication in specialist consultations [6] and the knowledge on characteristics of patients interested in a patient coach [7], support from a patient coach is not yet available for most patients visiting a medical specialist. Our results contribute to the understanding of the focus and conditions of patient coaching in secondary care, according to healthcare professionals.

The results need to be compared with the needs expressed by patients. Both perspectives can contribute to the development of a training for patient coaches. Future research should investigate to what extent patient coaching is able to reduce stress and support a patient in processing medical information.

Conclusions

According to healthcare professionals, patients who are generally or situationally vulnerable might benefit from a patient coach. Coaching should aim at reducing stress and an adequate processing of medical information before, during and after a consultation. A patient coach should be a trained professional and have medical knowledge.

Supplementary material

Supplementary material is available at *International Journal for Quality in Health Care* online.

Authors' contributions

IA was responsible for the study design, interviewing part of the participants and preparation of the data and was the primary author of the manuscript. PB acted as IA's main supervisor and provided feedback and support continuously during the phases of data collection, analysis and preparation of the manuscript. LG, AEMV and CS assisted the qualitative analysis. CS, PB and SvD provided critical comments and suggestions for revisions. CS, PB and SvD contributed in discussions regarding the background and purpose of the study. All authors read and approved the final manuscript.

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Prior presentations

Poster presentation at the EACH Bi-Annual Meeting in Porto, Portugal 2018. Oral abstract presentation at the LEARN meeting, Groningen, The Netherlands 2018.

Compliance with ethical standards

According to Dutch law, this study did not need medical ethical approval.

Data availability

The data underlying this article will be shared on reasonable request to the corresponding author.

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