Experiences and preferences of patients visiting an otorhinolaryngology outpatient clinic: a qualitative study

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Abstract

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Background Patient-centred care has received considerable attention in the last few decades, but the patients' perspective remains underexposed. This study reports on an in-depth evaluation of patients' experiences and preferences at an otorhinolaryngology outpatient department.

Methods Qualitative research was conducted on patients' experiences and preferences at an otorhinolaryngology outpatient department in an academic hospital. The study comprised two phases. First, semi-structured interviews were held with 22 patients. Second, results from the interviews were verified and deepened in a focus group ($N = 7$).

Results Overall, experience with patient-centred care was positive at the outpatient department. Three of the six dimensions of patient-centred care predominated in the interviews and the focus group: *information, communication and education; coordination and integration of care; and respect for patients' values, preferences and expressed needs*. The negative experiences were mostly in these dimensions. The dimensions *physical comfort* and *involvement of family and friends* were of lesser significance. Opinion on *emotional support – relieving fear and anxiety* differed as to whether this was the responsibility of the doctor or the patient.

Conclusion Qualitative research provided a deeper understanding of patients' experiences and preferences at an otorhinolaryngology outpatient department. Such an in-depth evaluation can be useful in the transition towards patient-centred care.

Introduction

Patient-centred care (PCC) has received considerable attention in the last few decades and is seen as a key element of care delivery.¹ The Institute of Medicine (IoM) defined PCC as an important area for improvement in health care.² Apart from being a goal in itself, PCC also leads to improved health outcomes.³ Besides lowering the costs per patient by reducing diagnostic testing, referrals and other health resource utilization, it improves patient well-being. PCC also increases adherence to treatment and is associated with improved quality of life.^{2–9}

Despite the interest in PCC, this concept has not been clearly defined in the literature.^{3,8,10–12} The IoM ascribes six dimensions to PCC: (i) respect for patients' values, preferences and expressed needs; (ii) information, communication and education; (iii) coordination and integration of care; (iv) emotional support – relieving fear and anxiety; (v) physical comfort; and (vi) involvement of family and friends² (see Table 1). As shown in a recent study, these dimensions adequately reflect patients' perceptions of PCC and their overall rating of care.¹² The IoM describes PCC as 'delivering care respectful of and responsive to individual patient preferences, needs, values, and ensuring that patient values guide all clinical decisions' (p.48).² From that perspective, efforts to deliver PCC would have to be based on knowledge about patients' expectations.¹³ But insight into their preferences and experiences is not obtained through straightforward questioning.¹⁴ Recently, an extensive review was published on the wide range of tools to measure PCC, some from a holistic perspective, others focused on its subcomponents.¹ While structured surveys are the most commonly used tool, questions have been raised about the usefulness of their results.^{1,15,16} Instead, in-depth qualitative analysis has proved to be more helpful for making improvements than survey data alone.^{8,14,15,17,18}

Although PCC is important in the field of otorhinolaryngology (ORL), to our knowledge,

no in-depth qualitative information has been gathered about patients' perspectives on PCC. Recent studies based on surveys have revealed differences in patient experience between subgroups of ORL patients. One implication is that their particular needs should be taken into account.^{13,19–21} In a more general sense, PCC means understanding a patient's unique needs and preferences in order to deliver care that is respectful to those preferences, which would entail obtaining in-depth knowledge for each patient. Some dimensions of PCC are more context specific, however, namely physical comfort and coordination and integration of care. Accordingly, PCC might also be measured for specific groups, such as ORL patients. Understanding their preferences and needs could facilitate efforts to improve the quality of care by explicitly defining PCC for this patient group. Subsequently, adequate outcome measures could be defined to evaluate the shift towards PCC.^{22,23} The aim of this study was to explore the patients' experiences and preferences at ORL outpatient clinics in terms of the six domains of PCC.

Methods

Study design

To ensure quality when reporting the study, the COREQ checklist was used.²⁴ It concerns the use of interviews and focus groups for collecting data in qualitative research. The items on the checklist are grouped into three domains: (i) research team and reflexivity; (ii) study design; and (iii) analysis and findings.

This study used a qualitative research design to determine the experiences and preferences of patients visiting the ORL outpatient clinic of the Maastricht University Medical Centre+ (MUMC+) in the Netherlands. At the clinic, over 20 000 patients are seen each year. The study was performed in two phases.

First, 22 semi-structured interviews were conducted with patients visiting the ORL outpatient clinic. The questions were based on the six dimensions of PCC as defined by the IoM.²

Table 1 Six dimensions of patient-centred care (PCC)²

Dimension	Definition
Respect for patients' values, preferences and expressed needs	Health care is patient-centred when precisely responding to a patient's preferences, needs and wishes
Information, communication and education	Health care is patient-centred if information on diagnosis, prognosis and treatment is responsive, attentive, trustworthy and tailored to the individual's needs
Coordination and integration of care	PCC ensures smooth care transitions to other settings, accurate and timely information transfer to the right persons
Emotional support – relieving fear and anxiety	PCC reacts to any fear, anxiety or other negative feelings caused by the illness or injury to both the patient and one's family
Physical comfort	PCC provides timely and tailored support to experienced shortness of breath, pain or other discomfort of a patient
Involvement of family and friends	In PCC, family and friends of patients are – if appropriate – to be involved in decision making, are supported as caregivers and respected and welcomed in the care delivery setting

On each dimension, patients were asked to share their experience at the ORL outpatient clinic and state their preferences for the future. The questions (listed in Appendix S1) were tested in a pilot before the start of the project. The interviews were conducted by a male researcher (GWH) who had a Master's degree and was a senior medical intern. The researcher, who was trained by an experienced interviewer, let the participants elaborate freely on the topics. After each interview, the researcher wrote down his perceptions, thereby creating field notes.

Second, a focus group (FG) comprising seven of the interview respondents was held to verify and deepen the findings. Three of the six dimensions of PCC were discussed in the FG: (i) *coordination and integration of care*; (ii) *communication, information and education*; and (iii) *emotional support*. These were either the dimensions most extensively discussed during the semi-structured interviews or the ones that evoked opposite opinions. For each dimension, at least one statement was formulated on which the respondents could elaborate. In total, six statements were discussed during the FG (Appendix S2). Three concerned *coordination and integration of care*; two concerned *communication, information and education*; and one statement referred to *emotional support*. At the end of the session, respondents were asked where they would give priority for improve-

ment. The FG was convened by two researchers (GWH and JVLZ), who let the participants freely elaborate on each statement and then summarized the outcomes. One of the researchers was male and the other female. Both hold a Master's degree; one researcher was a senior medical intern at the time of the study (GWH) and the other a PhD student (JVLZ). Both were well trained in interviewing.

Sampling strategy

Maximum variation sampling was used to select respondents.²⁵ Considering the importance of individual preferences and needs in PCC, it is crucial to take the heterogeneity among patients into account. Maximum variation sampling is conducive to searching for patterns shared among a heterogeneous group.²⁵ As the ORL outpatient clinic considers its population to be heterogeneous, maximum variation sampling was very suitable.

To enhance the probability of a representative selection of respondents, three criteria on which they should vary were formulated. Respondents had to vary in terms of: (i) subspecialism (ear, nose, throat, balance); (ii) degree of case complexity (simple vs. complex); and (iii) age category (either below or above 50 years old). Persons with head and neck cancer were excluded from the study, as they

are diagnosed and treated at the hospital's oncology centre. There, the organization of care, the physical environment and personnel differ from the outpatient clinic. These characteristics are likely to influence patients' answers to some of the questions of the interviews – questions directly related to organization of care and physical comfort, for instance. Therefore, these oncology patients' opinions would not reflect the experiences of the ORL outpatient clinic. As no standards exist for simple or complex cases within the ORL outpatient clinic, the degree of complexity was determined by the medical head of the department (BK). In addition, as the respondents had to be able to share experiences, patients were only included if they had visited the ORL outpatient clinic more than four times in the last 2 years.

Patients were deemed eligible for inclusion if they were scheduled for a visit to the ORL outpatient clinic. Two researchers (GWH, JWB) scanned the consultation calendar and selected eligible respondents, who were then approached by telephone. After consenting verbally to participate, respondents were sent information about the study by regular mail or e-mail. Interviews were scheduled either right before or after their consultation at the ORL outpatient clinic. Patients were asked not to mention their participation in order to keep the doctor blind to the study. The interviewer introduced himself as the researcher (not the care provider) to the patients once they reported to the reception desk. At that point, the researcher asked for written consent.

After the interview, patients were asked to participate in the FG. If willing, they were sent information by regular mail or e-mail about the date and content of the FG. At the start of the session, all participants were asked to give their written consent. Both researchers introduced themselves at the beginning of the FG, providing the participants with information on their professional background, the aims of the study and the procedure. The semi-structured interviews and the FG were held in the MUMC+. The study protocol was assessed by the Medical Ethical Commission of the MUMC+, but full consideration was deemed unnecessary under Dutch Law.

Analysis

A template approach²⁶ was chosen for the coding process. The codebook was based on the key elements of PCC as defined by the IoM. The interviews and the FG sessions were recorded and transcribed verbatim to increase validity.²⁷ The respondents did not give feedback on the transcripts. Two researchers (GWH, JVLZ) independently coded one of the transcripts and discussed the codebook until consensus was reached. The remaining 20 interviews¹ were then coded by one reviewer (GWH) using NVivo.²⁸ The answers were inserted in a data matrix in which the rows give the respondents and the columns contain the concepts from the codebook. Then two researchers (GWH, JB) independently transformed the 'thick descriptions' into 'thin descriptions' – that is summarizing respondents' answers.²⁷ Next, the thin descriptions were converted into summaries per concept by two researchers independently (GWH, JB). These summaries were discussed until consensus was reached. If necessary, a third researcher (JVLZ) joined the discussion and made a decision. The answers given by respondents in the FG were entered into a data matrix, with the rows showing the topics and the columns containing the answers. Two researchers (GWH, JVLZ) independently transformed the 'thick descriptions' into 'thin descriptions' which were then transformed into summaries. The summaries were discussed until consensus was reached. Finally, conclusions from the semi-structured interviews and the FG were compared by two researchers (GWH, JVLZ) to identify possible discrepancies, similarities and deeper insights.

Results

In total, 52 patients were approached and 25 agreed to participate in the study (response rate 48%). As those refusing were not obliged to say why, the reasons for not participating in the study are unknown. Three respondents dropped

¹During the analysis, the recording of respondent no. 6 proved to be unusable because of noise, so this respondent was not included in the final analysis.

out after being enrolled: one felt ill on the day of the interview; one did not show up; and one experienced scheduling problems that prevented him from joining in. No repeat interviews were carried out. Of the 22 respondents that did take part in the study, six attended the FG. One was accompanied by his wife, which brought the total up to seven FG members. Respondents' characteristics are summarized in Table 1. The duration of the interviews varied between 21 and 69 min (median 52 min), mostly depending on the complexity of the respondent's medical case (the more complex the case, the longer the interview). An overview of the main results from both the semi-structured interviews and the FG is presented in Table 2.

Respect for patients' values, preferences and expressed needs

On the dimension *respect for patients' values, preferences and expressed needs*, two main topics emerged from the analysis. First, the majority of the respondents were satisfied with how their preferences were being dealt with. One

respondent highlighted the willingness of the doctors to co-operate:

The doctor even reserved a different treatment room for me, only because I wanted to see the lesion myself. ... That was pleasant. Now I have evidence it is not something my mind just made up (respondent no. 9).

Three respondents reported a negative experience in which their preference could not be complied with; the preference concerned refusing appointments with specific physicians. Five respondents felt they had to be assertive at the ORL outpatient clinic in order to get respect for their preferences and needs. Second, with the exception of two respondents, all felt free to ask questions during consultations. Two respondents were less satisfied and felt that there was no opportunity to ask questions or that the answers to their questions were not targeted to the patient's level of knowledge.

Respondents in the FG stated that it is important to get an explanation when an expressed preference is not being complied with. They also found that being able to ask questions is a very important issue. Raising questions could be

Table 2 Basic characteristics of respondents (*n* = 22)

Nr.	Specialism	Degree of complexity	Sex	Age	Focus group participation
1	Vestibulology	High	F	53	No
2	Laryngology	High	F	57	No
3	Otology	Low	M	57	No
4	Laryngology	Low	F	59	Yes
5	Otology	High	F	24	Yes
6	Rhinology	Low	M	10+ father	No
7	Benign tumours	High	F	37	No
8	Otology	Low	M	8+ mother	No
9	Otology	High	M	57	Yes
10	Laryngology	High	F	46	No
11	Otology	High	M	54	Yes
12	Otology	High	F	63	No
13	Vestibulology	Low	F	68	Yes
14	Vestibulology	Low	M	65	Yes
15	Benign tumours	High	M	48	No
16	Laryngology	High	M	64	No
17	Rhinology	Low	F	76	No
18	Rhinology	Low	F	18	No
19	Vestibulology	Low	F	60	No
20	Vestibulology	High	F	29	No
21	Otology	High	F	68	No
22	Rhinology	Low	M	52	No

Table 3 Overview of results

Dimension	Results semi-structured interviews	Results Focus Group
<i>Respect for patients' values, expressed preferences and needs</i>		
Dealing with preferences	The majority of the respondents who expressed preferences were satisfied with the way their preferences were being dealt with. Three respondents expressed a preference which could not be granted. All three of these respondents missed a clear explanation for this. Five respondents stated that being assertive is necessary or at least helpful for having a satisfying experience at our outpatient clinic	The focus group mentioned that it is important to get an explanation when a preference cannot be granted
Dealing with questions	Except for two, all respondents felt free to ask questions. It is much appreciated when the doctor asks whether they have questions left at the end of the appointment. Two respondents were less satisfied and stated that there was either no room for questions or the answers to the questions were not targeted to their level of knowledge	The focus group concluded that it is most important for patients to feel free to ask questions. Expressing a calm attitude, asking the patient for a summary at the end of the consultation and having built a relationship with the patient are all factors that contribute to this
<i>Information, communication and education</i>		
Doctor–Patient	Except for one, all respondents described communication with their doctor as good and clear. Open and honest communication was noted to be important by three patients. Two patients (both acute epistaxis) underlined the importance of a stepwise explanation of the procedure to be followed	The focus group concluded that open and truly honest communication is very important. In general, members of the focus group did feel that this kind of open and honest communication exists at the ORL clinic
Administrative assistants	On average, respondents described communication at the reception desk as friendly, helpful and respectful. Three respondents experienced communication difficulties caused by planning problems. Respondents did, however, experience willingness to solve the problems	The focus group stated that administrative assistants should have an open attitude that shows willingness to solve problems
External communication	Four respondents reported unclear, untimely or no communication with their GP. Two respondents underlined the importance of the general practitioner being well informed	Not discussed in the focus group
Internal communication	All respondents felt their doctor was well informed before the consultation. Two respondents commented that a patient record file containing only text is insufficient in complex cases	The focus group stated that, in general, doctors are well informed before the consultation. They also noted that the patient file could be expanded with pictures, drawings and other multimedia to assist doctors
Information	Six respondents said they would appreciate additional information, either some background on the diagnosis, information about a function test or contact details for fellow patients. Two respondents stated that getting additional information is the patient's own responsibility. Three respondents explicitly appreciated an explanation of the scopic procedure	Respondents stated that in some cases they receive a lot of oral information, mainly concerning logistical procedures. Respondents saw room for improvement here – by means of a short explanation – as it is not always comprehensible to a patient

Table 3. Continued

Dimension	Results semi-structured interviews	Results Focus Group
<i>Coordination and integration of care</i>		
Planning	In general, respondents felt that the process runs smoothly. Respondents made a number of remarks about the planning system. First, they considered it awkward that it is impossible to plan more than 3 months in advance. Second, they regarded the planning system as moderately flexible when planning combined appointments	Respondents generally felt that the process runs smoothly. They mentioned the inflexibility of the planning system as a problem, in that it is impossible to plan more than 3 months in advance
Alternating doctors	For many respondents, being treated by different doctors is an important issue. In general, patients underlined the value of building a relationship with the doctor. In particular, patients with complicated cases or patients referred from other hospitals were unsatisfied with this practice	Discussing seeing different doctors at the outpatient clinic, it was apparent that patients need a trusted representative. Having a fixed supervisor, even just present at the first consultation, could already help the patient feel at home
Access times	The majority of the respondents did not refer to access times as problematic. Only two respondents mentioned problems with access times. Respondents needing an appointment with the vestibular specialist for a function test had access problems	The focus group mentioned that access is not the only problem, so is waiting time (also during the diagnostic phase). Discussing the topic, some nuances were made. To patients with low ADL restrictive, complex symptoms, the long waiting times were less problematic, compared to patients who are more severely affected by their symptoms. While explaining the reason for waiting times would diminish the amount of irritation, it would not be a solution
Waiting in the waiting room	Only two respondents made critical remarks about the wait at the outpatient clinic on the day of the appointment. Other respondents mentioned that waiting is taken for granted or that the doctor minimizes the problem with his/her attitude	Not discussed in the focus group
<i>Emotional support – relieving fear and anxiety</i>		
Emotional and psychological support	Approximately half of the respondents stated that little or no attention was given to emotional support. The majority of these respondents regarded this as normal or did not expect support. Three respondents (all vestibular patients) felt incongruence between the expected emotional support and the support received	The respondents in the focus group considered emotional support to be an important subject. Some were satisfied with the support received, some not. There is no consensus as to whether emotional support should be initiated by the doctor or the patient. Nor was consensus reached about the form of emotional support – whether the doctor would provide it or refer the patient to a psychologist
Social support	The majority of the respondents experienced sufficient attention for the social impact of their disease. Five (3 vestibular and 2 laryngology patients) mentioned that they would have appreciated more attention for this aspect of their disease	Not discussed in the focus group

Table 3. Continued

Dimension	Results semi-structured interviews	Results Focus Group
<i>Physical comfort</i>		
Outside the consultation room	Seven respondents preferred a high quality of care to a nice interior. Three respondents mentioned that feeling comfortable is the result of a good atmosphere rather than of the interior in itself. The majority of the respondents who mentioned the interior commented on the waiting area. However, there is no consensus on how the waiting area should look	Not discussed in the focus group
In the consultation room	All respondents, except one, admitted feeling comfortable in the consultation rooms at the outpatient clinic. Patients indicated that good communication, taking time for preferences and questions, and stepwise explanation of the physical examination helped them feel comfortable. This was especially true for painful interventions	Not discussed in the focus group
<i>Involvement of family and friends</i>		
Family and friends	With one exception, all respondents were satisfied with the way their family and friends are dealt with. Respondents valued the equal attention for family and friends	Not discussed in the focus group

stimulated by encouraging the clinician to show a calm attitude and ask the patient to summarize the information.

Information, communication and education

Within the dimension *information, communication and education*, five main topics emerged from the analysis. First, with exception of one person, all respondents were satisfied with their doctor–patient communication and described it as *good* and *clear*. This was verified by the respondents in the FG.

Second, respondents described communication with the administrative staff of the outpatient clinic as *friendly*, *helpful* and *respectful*. Some reported communication problems caused by planning mistakes. Nonetheless, those respondents noted a willingness to solve the problems once identified. The respondents in the FG considered a problem-solving approach to be of great importance in communication with the administrative staff.

Third, respondents reported some negative experiences with external communication, for instance with their GP. Four respondents mentioned external communication to be unclear, untimely or non-existent.

Fourth, all respondents thought their doctor was well prepared at the consultation and they experienced good internal communication. This assessment was verified by the respondents in the FG. During the semi-structured interviews as well as during the FG, respondents mentioned that adding multimedia to the patient file – such as pictures or drawings – would assist doctors in being prepared and transferring information among each other. As one respondent noted,

I feel that a doctor who doesn't know me really faces difficulties in getting an image of what he actually sees in my ear I think the patient file should be expanded. It shouldn't only contain written text but could be completed with pictures or movies (respondent no. 5).

Finally, respondents reported on the information they received at the outpatient clinic,

some saying they would have appreciated more guidance on, for instance, procedures or tests. In the FG, the information on logistical procedures in the hospital was considered extensive. Respondents mentioned that a brief explanation of logistical procedures would be helpful. As one FG member stated,

It is quite a lot that you need to do when they schedule you for surgery. I'm experienced by now, but if I weren't I'm sure I would have felt lost. What to do with all this information? If they would give a quick step-by-step explanation of what to expect, you'd feel better prepared (respondent no. 5, FG).

Coordination and integration of care

Four topics emerged within the dimension *coordination and integration of care*, namely planning, alternating doctors, access times and waiting in the waiting room.

With regard to planning, respondents experienced inflexibility in the planning system. Some were confronted with the impossibility of planning more than 3 months in advance, others with the impossibility of making combined appointments (at both the ORL outpatient clinic and the Audiology Centre, for instance) on short notice. As one respondent recounted,

Indeed, when did I call for the last time? I don't remember. Anyway, after the first phone call I tried two more times. But the schedule still wasn't there. And then, finally in November, the schedule was ready. That is quite short notice since it is now the beginning of December (respondent no. 20).

The impression of inflexibility was confirmed in the FG. Apart from the problems in the planning system, respondents experienced a efficient care process at the outpatient clinic. This too was confirmed by those in the FG.

Seeing different doctors at subsequent appointments was an important topic in most of the semi-structured interviews as well as in the FG. Negative experiences due to alternating doctors were reported by some patients, especially those with complex cases. As one respondent put it,

At almost every appointment I saw a different resident. (...) I had the feeling they didn't really know what to do with my case, I think that was the worst part. I needed to tell the same story over and over again. And every time that day's supervising doctor was called for a second opinion ... (respondent no. 7).

The topic of alternating doctors was discussed in more depth at the FG session. In the end, respondents thought that the reason why alternating doctors was a problem is that patients need some kind of trusted representative to build a relationship with. One respondent in the FG explained it thus:

I don't really mind the principle of seeing alternating doctors. I can see they all got the information from the last one. So essentially I am not against seeing alternating doctors. But not if each time you see a different doctor. You bond with your doctor. I like that (respondent no 11).

Members of the FG believed that being screened by a staff member for the first time – for complex cases – and knowing that this person is available as a supervisor for upcoming appointments would already improve the procedure.

Only two respondents mentioned negative experiences with access times, both concerned vestibular cases. When access was discussed in the FG, respondents mentioned that waiting times can be problematic throughout the entire process. Two nuances were made on this point, however. First, respondents thought that waiting times are more problematic for patients with high ADL restrictive and complex symptoms than they are for patients with low ADL restrictive and relatively simple symptoms. Second, respondents thought that waiting times would be less problematic if they were to be explained.

In general, respondents felt that waiting times on the day of the appointment were short.

Emotional support – relieving fear and anxiety

A distinction was made between emotional and psychological support, on the one hand, and social support, on the other. Half of the respon-

dents stated that little or no attention was given to emotional and psychological support. For the majority of these respondents, its neglect was in line with their expectations. Three respondents (all vestibular patients) reported incongruence between the expected support and the support received. One respondent said that

Until now I haven't experienced any emotional support. I do see a psychiatrist and psychologist. It was the GP, however, who referred me when I developed other problems as well (respondent no. 20).

During the FG, respondents highlighted the importance of emotional and psychological support. Furthermore, opinion in the FG differed as to whether enough emotional support was provided and if emotional support should be initiated by the doctor.

With respect to social support, the majority of the respondents felt that the doctor gave sufficient attention to the social impact of their disease. Five reported a negative experience, three of whom were vestibular patients and two laryngology patients. This topic was not addressed in the FG.

Physical comfort

For the dimension *physical comfort*, a distinction was made between time spent in the consultation room and outside of it. In general, comfort outside the consultation room was considered less important. Some even felt that physical comfort outside the waiting room is influenced by the atmosphere at the outpatient clinic rather than by the features of the interior itself. As one patient put it,

It is more the prospect of meeting nice and friendly people. You know a hospital is for medical reasons as sober as it is. We are not here to be cosy (respondent no. 9).

With respect to physical comfort within the consultation room, almost all patients reported positive experiences. Good communication, taking time for patients' physical preferences and giving a stepwise explanation of the physical examination were said to contribute to the patient's physical comfort.

Involvement of family and friends

Almost all respondents were positive about the involvement of family and friends. In general, they felt that these parties are given equal attention during the appointment. Only one respondent reported a negative experience, stating that her mother was completely ignored during the consultation. This dimension was not discussed in the FG.

Discussion

Relatively little is known about experiences and preferences for PCC at ORL outpatient departments. Some recent studies in that setting emphasize the unique needs of certain groups within the ORL population and the importance of further research into patient experiences in ORL.^{19–21} The present report provides deeper insight into patients' experiences with and preferences for PCC in ORL. Specifically, it offers three important insights.

First, using semi-structured interviews and a focus group, this study was able to distinguish areas of explicit importance to patients. In line with findings from patient satisfaction research,^{29,30} this study shows that respondents generally report positive experiences with the care at the outpatient clinic. During the semi-structured interviews, most of their remarks concerned the following dimensions: *information, communication and education; coordination and integration of care; and respect for patients' values, preferences and expressed needs*. Within these dimensions, they attached great importance to three types of action: building a trusting relationship with one's doctor; open and honest communication by all employees of the outpatient department; and the doctor conveying a calm attitude that gives a patient room to express preferences or ask questions. These findings corroborate with those of a recent study that explores patient experience with PCC at an inpatient acute care medical unit.³¹ In addition, our respondents said that being assertive was an important factor in having a positive experience at the outpatient

department. This too is in line with results in the literature.³¹

If respondents reported negative experiences at the outpatient department, they mostly concerned one of the same three dimensions. In general, respondents thought that the dimensions *physical comfort* and *involvement of family and friends* were of secondary significance. They either had satisfying experiences with regard to these latter dimensions or thought a particular dimension did not contribute significantly to their perception of a high quality of care. Opinions on the dimension *emotional support – relieving fear and anxiety* seemed to differ among the respondents. Although they do attach importance to this dimension, they seemed unsure whether attention for emotional support is the responsibility of the provider or the patient. In contrast, a study evaluating the predictability of the dimensions of PCC for overall quality of care in a general hospital population found the dimension *emotional support* to have the greatest influence.¹² This might imply that the relative importance of a dimension for patients differs between certain groups of patients.

A *second* important insight gained from this study is that patients with complex health problems differ from patients with relatively simple health problems in the way they attribute relative significance to the dimensions. Patients with high ADL restrictive, complex symptoms reported more negative experiences in the dimension *coordination and integration of care* and seemed to be more affected by the problems. For this group, seeing the same doctor and reducing waiting times in the process seemed to have greater importance than for patients with low ADL restrictive, relatively simple symptoms.

The *third* and probably most important insight is that a qualitative research design can lead to a deeper understanding of the needs and preferences of a patient population. An additional benefit is that patients are able to contribute to the process of improvement by offering suggestions on how negative experiences can be dealt with in the future. This

could be very helpful when thinking about redesigning health-care delivery towards more PCC. The challenges in shifting from a provider-centred care system to PCC are well known and described in the literature.^{10,22,31–34} This study adds to that literature by demonstrating that exploring patients' experiences and preferences in depth offers empirical grounds for thinking about and shifting towards PCC.

Limitations

The results of this study are comparable to those from similar studies in other settings or carried out with different research methods. Therefore, the results might be self-evident to some health-care professionals. However, this is the first attempt to explore the experiences and preferences of ORL patients in depth using qualitative research methods in order to create a scientific basis for the delivery of patient-centred care for this group of patients. In addition, this study shows that qualitative research can contribute to a sound understanding of patients' experiences and preferences. As this study was a first attempt to understand patients' perceptions of PCC as defined by the IoM, some interesting differences between subgroups of patients – patients with hearing loss vs. balance disturbance, for instance – are not examined here. It might be useful to investigate those differences in more detail in future research.

Using qualitative research methods can place some limitations on the generalizability and validity of the findings. The COREQ guidelines specify 32 items divided into three domains. These domains are said to influence the methodological robustness of qualitative studies.²⁴ The *first* concerns the research team and reflexivity. For this study, the interviews and focus group were led by a trained and experienced researcher who had no treatment relationship with the respondents that could influence their answers. The *second* domain concerns the study design, which influences the quality of the outcomes. For this study, the

framework of PCC set forth by the IoM was used as a guide, and maximum variation sampling was applied to select respondents. The sample size of the study population might be considered as medium. Nonetheless, using maximum variation sampling to select information-rich cases, narrowing the scope of the study by focusing on the six dimensions of PCC and conducting a focus group with the same respondents (i.e. repeated measures) decrease the need for a large sample.³⁵ The reasons for non-response are unknown. Therefore, the findings might be positively biased; that is, respondents with positive experiences might have been more willing to participate. It should be noted that this study was carried out in an academic hospital, and findings can be influenced by context-specific factors. *The third* domain covers the analysis and findings. Holding a focus group interview to verify and deepen the findings of the semi-structured interviews was seen as a means to overcome the tendency to give socially acceptable answers and to increase validity.

Conclusion

This report provides in-depth insight into patients' experiences and preferences at an ORL outpatient clinic. Using qualitative research methods to evaluate patient experiences, a distinction is made between the relative significance of dimensions of PCC for this patient population and differences are shown in attributed significance between subgroups of patients. The results imply that patients' perceptions of PCC might differ on the basis of characteristics such as disease complexity. Therefore, the findings underline the need to assess patients' perceptions of PCC carefully before initiating improvements in the field of PCC. In addition, although the methods used in this study led to an in-depth exploration of patients' perceptions of PCC at an ORL outpatient clinic, combining a range of research methods will lead to the most robust measure of PCC. Finally, the results of this study imply that patients are able to participate in projects to enhance quality by suggesting ideas for improvements and by explaining their perspectives. When

aiming to shift towards more PCC, it is therefore worthwhile to consult patients before planning improvement projects.

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Conflict of interest

The authors report that there is no conflict of interest to declare.

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Supporting Information

Additional Supporting Information may be found in the online version of this article:

Appendix S1: (Translated) Interview guide.

Appendix S2: (Translated) Focus group guide.

References

- 1 de Silva D. Helping measure person-centred care. *A Review of Evidence about Commonly Used Approaches and Tools Used to Help Measure Person-Centred Care*. London: The Health Foundation, 2014.
- 2 Institute of Medicine. *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, DC: National Academies Press, 2001.
- 3 de Boer D, Delnoij D, Rademakers J. The importance of patient-centered care for various patient groups. *Patient Education and Counseling*, 2013; **90**: 405–410.
- 4 Bauman AE, Fardy HJ, Harris PG. Getting it right: why bother with patient-centred care?

- Medical Journal of Australia*, 2003; **179**: 253–256.
- 5 Bertakis KD, Azari R. Patient-centered care is associated with decreased health care utilization. *Journal of the American Board of Family Medicine*, 2011; **24**: 229–239.
- 6 Orn M. Impact of incorporating a patient-centered care model. *Journal for Nurses in Staff Development*, 2010; **26**: 164–169.
- 7 Richards T. Enlist the patients' help. *BMJ*, 2011; **343**: d5827.
- 8 Stewart M, Brown JB, Donner A *et al.* The impact of patient-centered care on outcomes. *Journal of Family Practice*, 2000; **49**: 796–804.
- 9 Hunter R, Carlson E. Finding the fit: patient-centered care. *Nursing Management*, 2014; **45**: 38–43.
- 10 Sidani S, Fox M. Patient-centered care: clarification of its specific elements to facilitate interprofessional care. *Journal of Interprofessional Care*, 2013; **28**: 134–141.
- 11 DiGioia A 3rd, Lorenz H, Greenhouse PK, Bertoty DA, Rocks SD. A patient-centered model to improve metrics without cost increase: viewing all care through the eyes of patients and families. *Journal of Nursing Administration*, 2010; **40**: 540–546.
- 12 Shulman HM, Sullivan KM, Weiden PL *et al.* Chronic graft-versus-host syndrome in man. A long-term clinicopathologic study of 20 Seattle patients. *American Journal of Medicine*, 1980; **69**: 204–217.
- 13 Freitag M, Carroll VS. Handoff communication: using failure modes and effects analysis to improve the transition in care process. *Quality Management in Health care*, 2011; **20**: 103–109.
- 14 Giesen P, Smits M, Huibers L, Grol R, Wensing M. Quality of after-hours primary care in the Netherlands: a narrative review. *Annals of Internal Medicine*, 2011; **155**: 108–113.
- 15 Tsianakas V, Maben J, Wiseman T *et al.* Using patients' experiences to identify priorities for quality improvement in breast cancer care: patient narratives, surveys or both? *BMC Health Services Research*, 2012; **12**: 271.
- 16 Coyle J, Williams B. Valuing people as individuals: development of an instrument through a survey of person-centredness in secondary care. *Journal of Advanced Nursing*, 2001; **36**: 450–459.
- 17 Little P, Everitt H, Williamson I *et al.* Preferences of patients for patient centred approach to consultation in primary care: observational study. *BMJ*, 2001; **322**: 468–472.
- 18 Stewart M. Towards a global definition of patient centred care. *BMJ*, 2001; **322**: 444–445.
- 19 Boss EF, Thompson RE. Patient satisfaction in otolaryngology: can academic institutions compete? *Laryngoscope*, 2012; **122**: 1000–1009.
- 20 Boss EF, Thompson RE. Patient experience in the pediatric otolaryngology clinic: does the teaching setting influence parent satisfaction? *International Journal of Pediatric Otorhinolaryngology*, 2013; **77**: 59–64.
- 21 Nieman CL, Benke JR, Ishman SL, Smith DF, Boss EF. Whose experience is measured? A pilot study of patient satisfaction demographics in pediatric otolaryngology. *Laryngoscope*, 2014; **124**: 290–294.
- 22 Davidoff RA, Hackman JC. Hyperpolarization of frog primary afferent fibres caused by activation of a sodium pump. *Journal of Physiology*, 1980; **302**: 297–309.
- 23 Hackman BW. Brunel's half-sovereign. *Lancet*, 1980; **1**: 1038.
- 24 Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 2007; **19**: 349–357.
- 25 Patton M. *Qualitative Evaluation and Research Methods*. Beverly Hills, CA: Sage, 1990.
- 26 Fereday J, Muir-Cochrane E. Demonstrating rigor using thematic analysis: a hybrid approach of inductive and deductive coding and theme development. *International Journal of Qualitative Methods*, 2006; **5**: 80–92.
- 27 Miles M, Huberman M. *Qualitative Data Analysis: An Expanded Sourcebook*, 2nd edn. Thousand Oaks, CA: Sage, 1994.
- 28 QSR International. NVivo qualitative data analysis software. Version 9 [computer program], 2010.
- 29 Crow R, Gage H, Hampson S *et al.* The measurement of satisfaction with healthcare: implications for practice from a systematic review of the literature. *Health Technology Assessment*, 2002; **6**: 1–244.
- 30 Kleefstra S, Kool R, Zandbelt L, de Haes J. An instrument assessing patient satisfaction with day care in hospitals. *BMC Health Services Research*, 2012; **12**: 125.
- 31 Ferguson LM, Ward H, Card S, Sheppard S, McMurtry J. Putting the 'patient' back into patient-centred care: an education perspective. *Nurse Education in Practice*, 2013; **13**: 283–287.
- 32 Epstein RM, Street RL Jr. The values and value of patient-centered care. *Annals of Family Medicine*, 2011; **9**: 100–103.
- 33 van der Eijk M, Nijhuis FA, Faber MJ, Bloem BR. Moving from physician-centered care towards patient-centered care for Parkinson's disease patients. *Parkinsonism & Related Disorders*, 2013; **19**: 923–927.
- 34 McInnes DK. Don't forget patients in patient-centered care. *Health Affairs*, 2010; **29**: 2127; author reply 2128.
- 35 Morse JM. Determining sample size. *Qualitative Health Research*, 2000; **10**: 3–5.