



2016

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## Recommended Citation

Berglund, Britta E. and Westerlund, Irene (2016) "Patient organizations and primary care development: reflections by patients with chronic diseases," *Patient Experience Journal*: Vol. 3: Iss. 2, Article 6.

Available at: <http://pxjournal.org/journal/vol3/iss2/6>

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## **Cover Page Footnote**

**Acknowledgement** We want to express our sincere gratitude to the different patient organizations and their local members participating in the focus group interviews. **Funding** The project was one part of the project named 'A well-functioning primary care for patients with chronic diseases' based at the Swedish Disability Federation (Handikappförbunden) ([www.hso.se](http://www.hso.se)) and funded by the Social Department of the Swedish Government. Authors declare no conflict of interest.

## Patient organizations and primary care development: reflections by patients with chronic diseases

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### Abstract

To explore how patients with chronic diseases, as well as members of patient organizations, perceive primary care and how they think about how to participate in primary care development. Focus group interviews with 28 patients in three regions in Sweden were conducted. We identified four themes: Availability of care, How to be met by professionals, Information needs and Continuity and prevention in care. Important was to meet the same doctor at every visit and to be met with empathy and knowledge about your disease. Suggestions about better use of technical information services, introduction of a coordinator in the waiting room and longer and varied open hours came up. The information needs for newly diagnosed and those with a long disease trajectory differed and care treatment plans were asked for by many participants. Discussions between patient organizations about how to participate in education of health care professionals were recommended. Patients' with chronic diseases want to take more active part in their own care. By promoting more contacts between patient organizations, influence on the politic agendas may be achieved. To achieve effects, the patient organizations should be proposed to be included and to activate themselves about these results. If so, a stronger patient voice may be heard in the society. A change in the paternalistic philosophy in primary health care is also needed so the patients' rights and contribution will be acknowledged and joint education with health professionals could be one way.

### Keywords

Focus groups, chronic diseases, patient organizations, primary care, development

### Introduction

Primary care is the first choice of care for the public and about 1000 health care centers are operational in Sweden. Patients with multiple chronic conditions frequently visit and challenge primary health care, but they still depend on self-care and own ability to access health-care services.<sup>1</sup> The number of complaints about availability, encounters and maltreatments in care are increasing.<sup>2</sup> Several reports have pointed out that patients with chronic diseases are disappointed both by the quality and availability of today's health care.<sup>2,3</sup> Some patient groups with chronic diseases feel neglected, and not treated with compassion.<sup>4</sup>

In order to give attention to such issues, the Swedish government decided on a National strategy and a Patient Law, with keywords as knowledge, support and prevention for chronic diseases in primary care.<sup>5,6</sup> The patient can ask for a second opinion and primary care services in another part of the country, a contact person for the patient should be assigned, and information about health, about treatment alternatives and prevention is supposed to increase. According to this law, the patient is more evidently expected to participate in own care.

### Background

Health care providers have by tradition a monopoly on determining the course and outcome of patient treatment.<sup>7</sup> The professionals are considered to be the experts, and the ideal patient is both compliant and self-reliant.<sup>1</sup> However, patients with chronic diseases in Europe want to have a say in how the health care providers are held accountable, and as well want to have an independent say in priority setting and appraisal.<sup>8</sup> Patients also want to have a say when choosing their health care provider and want to be involved in treatment decisions.<sup>9</sup>

According to the study of Van Houdt et al.<sup>10</sup>, roles and quality of relationship between health care professionals and patients as well as exchange of information, setting and sharing of common goals to improve coordination and quality of care are important areas to work with.<sup>12</sup> When looking at what criteria for good quality care patients' put forward in research, the highest rated are information about disease, medicines, treatment and results in simple, jargon free language.<sup>13</sup> A more active role in health care decision making is today asked for by patient organizations<sup>9</sup>, but a gap is detected between the time patients' consider reasonable to make changes and the

time it takes for health care to implement decisions visible for patients' to see.<sup>7</sup>

## The Current Project

The Swedish Disability Federation received governmental funding for the project called 'A well-functioning primary care for persons with chronic diseases'. The focus was to investigate and identify what critical factors are a prerequisite for good quality care in primary health care centers and how patient organizations and staff can cooperate to achieve this goal. The project team comprised from May 2014 the project leader (BB) and one person from each of four associations: the Asthma and Allergy Association, the Diabetes Association, the Heart/Lung Association and the Rheumatic Association. All thirty-nine organizations, the members of the Swedish Disability Federation, embraced a reference group. In order to investigate how staff in different health care centers reason about good quality care for patients with chronic diseases, the project team visited nine health care centers in different regions of Sweden in the fall 2014. Five of these centers were located in rural districts and four in urban locations. In these meetings, we focused on how the forthcoming Patient Law<sup>6</sup> was going to be introduced in the program for the patients with chronic diseases. These discussions were then followed up with focus groups with patients, as reported in the present paper.

The aim for the focus group interviews was to explore how patients with chronic diseases perceive primary care and think about how to participate in primary health care development.

## Methods

### Design of the study

Focus groups with a semi-structured interview schedule.

### Sample

Six focus groups with patients were organized in three regions in Sweden: the North, the Mid and the Southeast

Region. The local patients' organizations were invited to assign participants to the focus groups. In each of these regions, one interview with persons over 50 years of age and one with persons below 50 years of age were performed. This was made as an effort to see if questions about care differed between younger and older persons. In total, 28 persons participated, and they were 14 females and 14 males with experiences of primary health care and engaged in 18 different patient organizations (Table 1).

### Collection of data

One trained discussion leader (IW) and two observers from the project team, as well familiar with making interviews, participated in each focus group interview. The interviews focused on the participants' experiences as patients in primary health care. After a short introduction about the aim of the project, the interviewer started by asking 'Can you tell me about your experiences from meetings in primary health care?' The focus was not on the participant's diagnoses, age or geographical status but to identify how the patient with a chronic disease perceived their meetings with primary health care. Open follow-up and personal questions were appreciated.

The interviews were held in a separate room situated at the premises of the umbrella organization working together with the local patient organizations in the region. The group discussions lasted for about two hours, were audio taped and notes were taken by the observers. A minor gift voucher was given to the participants as compensation for their time.

### Data analysis

The transcribed data was analyzed with qualitative content analysis. Themes and patterns were in focus in our discussions until agreement was achieved<sup>12</sup>. To ensure grounding of the data and representation of the study sample, quotes were used to provide an integrated account of the participants' experiences.

### Ethical considerations

No ethical application was made since the interviews were included as a part of the current project in primary health care. Information about the aim for the focus group

**Table 1. Participants in Focus Groups (n = 28)**

	North n	Mid n	South n	Total n	
<50	5	4	3	12	
>51	6	5	5	16	
Females	3	5	6	14	
Males	8	4	2	14	
	11	9	8		28

interviews and a question about their interest to participate was given by e-mails and at meetings to all 39 organizations in the Swedish Disability Federation. Eighteen (72%) organizations assigned individuals to participate. Some of these individuals were already involved in their organizations activities.

## Results

Four themes were identified as general by the participants: Availability of care, How to be met by professionals, Information needs, and Continuity and prevention in care.

### Availability of care

One common theme was the use of technical aids in care delivery. For example, computers for documentation of care are available today and could be used more which the participants thought could increase availability to care in different clinics. Some participants mentioned that persons with cognitive difficulties or those who are unfamiliar with the phone system, may have difficulties to reach the health care center by pushbutton telephone, due to having to choose which button to touch. Extended phone hours were also wanted and the possibility to ask for a doctor or another specialist at the same time as asking for an additional visit. Also, some health centers offer to make a return call at a specific time if you state your phone number, and that was much appreciated.

*'...sometimes you need just to get in touch with the physician or the nurse with a question.'*

*'If the phone hours are unavailable, you may have to go to the emergency department at the hospital.'*

Participants also recommended a coordinator at the health center to be established in order to support patients. Such a person could be trained by the organizations in how to meet and aid different patient groups. Some persons need help to fill in a form and others need to find an organization with information about their diagnosis.

*'The link to the district nurse is not existing, you have to look her up to make an appointment... but the contact nurse is fantastic, she takes time to listen to me, and she can be helpful with evaluations since she knows me'*

The open hours at the health center were too limited according to the participants' experiences. Several persons mentioned that it would be great if the health care centers could be open in evenings and weekends as well as in daytime. Sometimes an acute problem is on hand and then there is a risk that the patient has to go to the emergency

department at the hospital. If the health care center was available, less hospital visits would be necessary.

*'It is too difficult to get in touch with health care ...it takes too much effort, I can't do that.'*

Another interesting issue was the debate about a national system with all patient's medical journals, but the thoughts about it differed in the groups. Some participants meant that it could be worthy if it would increase better evaluation of the patient's needs. Others emphasized that it could as well present a security problem with a risk to be wrongly treated. However, the groups agreed upon that patients need their medical journals in order to participate in own care.

*'I asked the doctor if he could see in the journal that I have other diagnoses too, but he couldn't see that, and this means you can only have treatment for just one problem and he cannot see my whole picture. This caused me to get the wrong medication because it did not fit with the other medication I had.'*

### How to be met by professionals

A common theme focused on the importance to be seen and met with empathy, knowledge and competence by the professionals. If the physician takes time to check the medical journal with the aim to understand the patient's whole picture, the risk to deliver the wrong treatment can be limited. Additional time for the visit is asked for by the patient. In order to have a dialogue about care on equal terms the patient needs to have access to the readable medical journal which implies a simpler way to write and document care.

*'Everyone should read your own medical journal to see how the doctor plans care for you ... I have seen several wrong notes in my journals, it is important that everything is correct because you don't meet the same doctor every time and you can risk being incorrectly treated ...' The specialists in primary care are scarce and the cooperation between specialist and primary care is lacking ... the health care centers should create networks between other centers to give-and-take experiences and knowledge.'*

### Information needs

The participants meant that a person who has a chronic disease wants to have a dialogue with care professionals. The interviews pointed to the importance of correct and understandable information when a person receives a diagnosis, since it is important to gain knowledge about the diagnosis and how to manage daily life.

*'You get a diagnosis but nothing about what it means how to cope with it, and they are not interested to hear my perspective, they only ask about my problems.'*

*'All health care centers should give information about patient organizations, and arrangements should be made for patient organizations and health care to cooperate together ... because ways to cooperate between organizations is necessary.'*

### **Continuity and prevention**

The participants stressed that patients with chronic diseases often have a complex physical status that demands several activities as daily training, physiotherapy and other care. Preventive care is therefore important. Resources such as professionals (dieticians, physiotherapists and other allied care professionals) are needed to create teams for care of these patients.

*'A big problem is when you are not offered an additional visit, then you cannot take the responsibility for your treatment and the risk for acute visits increase.'*

None of the participants reported that they had a health plan or evaluation goals given from their primary care provider. Prevention and treatment goals are generally reported as lacking by the patients. Still, information about the possibility to ask for health plans is given on many primary health care homepages.

*'More preventive work is needed, groups with dietician about food, about smoking cessation, giving foot care if you need that, correct training instructions with physiotherapists.'*

*'Preventive work should start in schools and in companies, insecurity makes you not want to wait, then you turn to the emergency department instead.'*

### **Discussion**

We found evidence in these focus group discussions that patients, both younger and elderly, wanted to contribute to the communication process in their local primary health care. In order to function well in such a position, the organizations need to educate their members. The professional perspective has raised issues about how competent patient representatives for the development processes are selected. The ideal patient representative should have experienced health problems, in order to represent not only own views but the collected experiences of his/her delegating group. Also, an understanding in patients about evidence-based methods would be helpful to relate to patients' aspects of health care.<sup>13</sup>

Creation of knowledge includes developing a public health program or intervention and to make knowledge available within an organization<sup>14</sup>. Patient organizations have three roles in the society: to be a voice for the own group in the society, to be supportive for their own group with information and activities and to be administrative with funding from government or the health care system. The patient organizations knowledge about how to meet people with chronic conditions also indicates a profound knowledge about diagnoses. County councils and communities are responsible for their own budget and decisions and they frequently need patients as representatives in committees. New ways to organize health care and new technical systems are challenging for the patient organizations<sup>14</sup>. This puts demands on the organizations to allocate competent persons that can take on this task to contribute with the perspective of the whole group.

In the present study, availability to primary care and how you are met as a patient were discussed in all focus groups. According to the study of Van Houdt et al.<sup>10</sup>, roles and quality of relationship between health care professionals and patients as well as exchange of information and sharing of common goals to improve coordination and quality of care are important areas to work with<sup>10</sup>. When looking at what criteria for good quality care patients' put forward in research, highest rated are information about disease, medicines, treatment and results in simple, jargon free language.<sup>11</sup> These points are applicable for the results of the present study as well. Other points are that the health system gives medical advice when needed, has a suitable range of therapies, coordinated procedures, and integrated and continuous care. Patients want to have a say in how the health care providers are held accountable, and also to have an independent say in priority setting and appraisal. Much valued were also the importance of methods being approved, hygienic and safe, that risks are identified and responsible care and follow-up is provided.<sup>11</sup> On the other hand, the burden of treatment can be exhausting when the patient is trying to overcome poorly organized care and inadequate continuity.<sup>15</sup>

Being met with respect was identified by all respondents as an important factor in our study. Also Abrahamsson et al.<sup>16</sup> showed that interpersonal aspects of consultations are important for patient satisfaction, such as contact quality, relationship continuity and responsiveness of the encounter, regardless of whether met with a nurse or a physician.<sup>16</sup> In another systematic review to find measures of patient's active participation in encounters with health care, three conceptual frameworks were identified as empowerment and self-efficacy, therapeutic alliance and satisfaction.<sup>17</sup> Additionally, to look for evidence on the effects of use of services, quality of care and health of patients has been underlined.<sup>18</sup>

Strategies and routines for how to cooperate between authorities and organizations for the public good are needed in the society. A change in the paternalistic philosophy to patient-professional relationship, partnership in services and recognizing the patient's knowledge as well as training the patients' might increase the effectiveness of health care.<sup>7,9</sup> In the present study, cooperation was asked for between specialist and primary health care, as well as between patient organizations, and they ask for a more active role in health care decision making.<sup>8</sup> A supportive and understanding policy environment is needed between the private sector and government organizations to think through options and get a process going to work for social change.<sup>2</sup>

### Limitations

The participants were not randomly chosen, they were assigned by their local associations, which might influence the result. Not all the invited organizations took part in the focus group interviews, one reason is that some of their members generally only visit specialist care. Another limitation might be that the focus groups were performed in only three regions of the country. However, in several meetings with the patient organizations the same issues have been in focus. From this experience, we therefore want to underline that our results indicate the current perspective of most of the Swedish patient organizations.

### Conclusion

Patients' with chronic diseases want to take more active part in their own care. By promoting more contacts between patient organizations, influence on the politic agendas may be achieved. To achieve effects, the patient organizations should be proposed to be included and to activate themselves about the results from this study. If so, a stronger patient voice may be heard in the society. A change in the paternalistic philosophy in primary health care is also needed so the patients' rights and contribution will be acknowledged and joint education with health professionals could be one way.

### Suggestions for future research

If patient organizations are to be fully functioning as a major support for primary health care development, there is a need for debate about the changing landscape of information service and production. Important is as well to find ways and structures for communication and financing between primary health care, patient organizations and politicians.<sup>19,20</sup> More studies are needed about efficiency, quality of life and patient satisfaction in primary health care.<sup>18</sup> The decisions taken in politics are to be implemented by health care providers and a supportive

environment would be positive for increased knowledge in these areas.

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