



*Pain Care Vision 2023*

# **Experiences of handling daily life with chronic pain and preferences towards primary care - A qualitative report from a workshop**

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# Preface

Chronic pain is a complex public health problem that affects around 20% of the European population. It confers suffering and economic hardship at the individual level but also high costs for employers, health care systems and society at large. A report by the National Collaborative Group for Knowledge Management (NSK) from 2016, identified shortcomings and unjustifiable differences in care and treatment of persons with chronic pain in Sweden. It presented lacks in competence and structure for the treatment in primary care, and a shortage of doctors, physiotherapists, and nurses. In interviews, with patient organizations<sup>1</sup>, the care was considered unequal with shortcomings in treatment, accessibility, and competence of the profession both in primary and specialist care. Two reports, from 2014 and 2019, addressing pain care in Region Västra Götaland confirm the picture of deficiencies in pain care.

The project Pain Care Vision 2030 started in response to the reports noted above and the current changes facing health care closer to patients via primary care and local hospitals, a knowledge organization, and possibilities with digitalization. Finally, the foundation of the project by Vinnova's through the announcement of *Vision-Driven Health* in the autumn of 2019. The aim of Pain Care Vision 2030 was to develop a vision, and sub-goals to initiate improvements in primary care support for people with chronic pain in one of the largest regions in Sweden.

This report is a presentation on the material from a workshop within the project in which 15 persons with chronic pain discussed how they handle everyday life and interact with primary care, and their thoughts on how primary care ought to offer support. The workshop material was structured according to a qualitative content analysis by two nursing students Ebba Ranås and Amanda Dahlrot, as part of their bachelor's degree in nursing (RN). They were supervised by Linda Ahlstrom (PhD, MSc Clinical Advanced Nursing) and supported by the project leader for Pain Care Vision 2030, Anna Grimby-Ekman (Associate Professor).

Thank you to all individuals with chronic pain participating in the workshop, sharing their experiences and thoughts. Thank you to Swedish Rheumatism Association and Sweden's innovation agency Vinnova, which have financially supported the work

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**Pain Care Vision 2030**

**VINNOVA**

**Reumatiker  
förbundet**

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# Background

One in five Europeans suffer from chronic pain (1), and it is more prevalent among women and in older age (2). Furthermore, chronic pain puts a burden on society; in Sweden the estimated mean yearly cost for one person living with chronic pain is 6400 Euro (3). For persons with severe chronic pain, contact with primary care is a large part of their everyday life (1).

Chronic pain implies long-term suffering for the person. The sensation of pain is neither strictly physical or psychological but is commonly described as consisting of sensory, cognitive, and behavioural parts. Hence, pain is always subjective (5, 6). Chronic pain is associated with multimorbidity, sleep problems, depression, anxiety, lower quality of life and often being on sick leave (2, 7, 8). One out of three persons dealing with chronic pain state that the pain limits them to the extent that they can't live their life freely and be independent, and they often feel misunderstood by family and friends (1). Persons with chronic pain often experience lack of empathy and disbelief about their pain (1, 8). The outcome of coping with chronic pain could be influenced by an individual's approach, defensive or offensive behaviours, and choices related to their pain self-efficacy. Their own perceived self-efficacy and belief and trust in how to handle a specific situation can affect their health outcome (9).

Health care workers will most likely meet persons who are suffering, and particularly from pain. To have the courage to interact with a person's suffering is hard and uncomfortable, but to avoid it is a disservice to the suffering person, and sometimes little is required to meet the person's needs (10). In person-centred care patients are seen as persons who are more than their illness. The individual's experience of their illness and the context of the person's life is the key for health care personnel to be able to give the right support, and thereby promote health and wellbeing (11). Still today, results show that up to 80% of primary care physicians consider that persons with chronic pain are not given optimal treatment and care (13). Thus, it is highly relevant to investigate how persons with chronic pain experience their interaction with health care and how they can be supported.

The aim of this report is to present results from a workshop within the project Pain Care Vision 2030 in which 15 persons with chronic pain discussed how they handle everyday life and interact with primary care, and their thoughts on how primary care ought to offer support. The findings of this report could provide important information for health care workers to develop primary care for persons dealing with chronic pain.

# Method

## Project setting

The Swedish health care organization is primarily based on taxes and provided by the public sector (14). This report is part of the planning project Pain Care Vision 2030. In the project Pain Care Vision 2030 the aim was to describe areas of need, propose a project structure and innovative future projects regarding issues in chronic pain and primary care. A cornerstone was the vision of person-centred and evidence-based primary care for persons living with chronic pain. One important task in the project was to get feedback, knowledge, and experience of health care from individuals with chronic pain. This was achieved by arranging a workshop inviting persons with chronic pain, during which activities were conducted regarding primary care and living with chronic pain.

## Data collection

Potential participants were invited, via their patient organisations (Headache Patient Association, Fibromyalgia Patient Association and Rheumatism Patient Association), to participate in the workshop. Persons interested in the workshop were informed about the project Pain Care Vision 2030 and the aim with the workshop through email. At the start of the workshop, participants were again informed about the aim with the project Pain Care Vision 2030, the activities during the workshop and the use of the anonymous material created during the workshop in a coming report. The workshop was conducted in Gothenburg.

In total, 21 persons signed up through email to participate in the workshop. On the day of the workshop, 15 of these 21 attended, 3 men and 12 women, aged 33-79 years. Reasons given by those who did not participate were illness (two persons), practical reasons (two persons), chronic pain-related fatigue (one person), and unclear (one person). All participants were proficient in both written and spoken Swedish.

The workshop activities consisted of three parts and were led by an independent moderator who facilitated the discussion. The moderator was not taking part in the Pain Care Vision 2030 project. In part I, the participants were asked to interview each other, two by two, about how they handle situations in their everyday life in relation to their pain: in their home; outside of their home; when encountering health care; and in other situations. Notes were taken by the participants and then presented in workshop discussions led by the moderator. In part II, participants were asked to discuss, in groups of four or five, what the perfect encounter with primary care would be like. Notes on their discussion and thoughts were taken by the participants and then presented in the following focus group discussion led by the moderator. In part

III, the participants were presented with three innovation projects in relation to their everyday situation living with chronic pain, and they were asked to individually write down responses and ideas about these. The three innovation projects concerned 1) a primary care digital pain school, 2) a 1177 support tool to create a profile before and between healthcare contacts, and 3) regular support based on online and live contact (i.e., continuity in health care contact and over time). The participants' notes were presented in a group discussion led by the moderator. After the workshop, the moderator compiled a short summary report based on the participants' notes and the focus group discussions.

## Qualitative analysis

In this report we wanted to present a more comprehensive report based on the material from the workshop. The data were analyzed using content analysis according to Graneheim and Lundman (15). The unit of analysis consists of data from the anonymous workshop notes, the focus group discussions, and the moderator's synthesis report of parts I, II and III. The material was structured as *meaning units*, that were extracted in accordance with the aim stated above for this report and labeled with numbers to determine which part of the focus group the text came from (for example, part I was labeled A1, A2 and so on and part II B1, B2 and so on). These *meaning units* were then condensed and abstracted and afterwards labeled with a code. The codes were brought together by similarities and differences into subcategories. Thereafter, categories from the Standards for Reporting on Qualitative Research (SRQR) checklist were used (16).

## Results

The main theme identified was that a person with chronic pain develops a skill of ***Adaptability to handle everyday life*** (Table 1). This theme comprised domains representing both an individual perspective, ***The person - body and soul***, and their relation to health care, ***The person - interacting with health care***.

***The person - body and soul*** comprised the categories *Taking charge of everyday life* and *Empowerment*. ***The person - interacting with health care*** comprised the categories *Persons' contact with primary care organization* and *Treated with respect*.

Each of these categories comprised three to four sub-categories presented in Table 1 and described in the text below.

**Table 1.** Sub-categories, categories, domains, and the theme, based on the analysis of the material regarding the persons with chronic pain experiences of handling their everyday life, as well as their preferences in the primary care support.

Sub-category	Category	Domain	Theme
Initiating better health care	Taking charge of everyday life	The person - Body and soul	Adaptability to handle everyday life
Planning their everyday life			
Seeking support and assistance			
Optimizing their body position	Finding empowerment		
Using complementary treatment			
Finding an inner strength			
Availability of primary care	Contact with primary care organization	The person - Interacting with health care	
Continuity in care			
Interprofessional care			
Digital tools as a complement			
Wish for better partnership	Treated with respect		
To be taken seriously			
Need for a holistic view			

## Domain 1: The person - Body and soul

The first domain illustrates how persons with chronic pain use their body and soul to adapt and condition themselves in everyday situations.

### Category 1.1: Taking charge of their everyday life

Persons with chronic pain take charge of their everyday life by *initiating better health care*. They seek information about their pain, share this information with health care personnel, write down their questions and experiences, persist with questioning, and give suggestions about their care. When they feel unsatisfied with their care, they seek treatment from another health care provider and contact different professions to create their own interprofessional pain management team. The persons with chronic pain expressed that it is necessary for them to know a lot and to be persistent to make things happen.

Persons with chronic pain take charge of their everyday life by *planning their everyday life*. By living with their pain, they have realised which activities require them to rest the day before and after, and how much work, cleaning, cooking, they are able to accomplish during the day or week. The persons with chronic pain expressed that to acquire more knowledge about their disease and living a more balanced life, they could see that it makes a positive difference.

Persons with chronic pain say that they themselves need to be active in *seeking support and assistance*. Some find strength in their family and friends to keep fighting for appropriate health care. Some seek support from their health care provider and find it, for example, by being introduced to associations for persons with chronic pain or by attending information meetings about their disease. However, when their desired support is not provided by the health care provider, they feel as if they are left to suffer and deal with their pain on their own.

### **Category 1.2: Finding empowerment**

To handle everyday life with chronic pain, some of the persons used different practical techniques to find empowerment. *Optimizing their body position* was found to be a technique that was used in different settings. Some persons are forced to take a longer route when using public transport since they must sit down to optimize their body position, which delays their plans for the day. Some optimized their entire workspace and some their sleeping arrangements. This constant optimization puts stress on their mental and physical wellbeing. The persons with chronic pain expressed that they need to be inventive, and for example dare to solve practical problems in an unconventional way.

Another way to find empowerment was by *using complementary treatment* such as naturopathy, acupuncture, massage, cognitive behavioural therapy (CBT), yoga, walks, jogs, strength training, physiotherapy, swimming, mindfulness, qigong, breathing exercises, transcutaneous electrical nerve stimulation (TENS), a heat pad, or a mouthguard.

*Finding an inner strength* by trying to ignore the negative influences and focus on the good helped some to improve their mental state. Also, finding the strength within themselves to face bad treatment from health care personnel was empowering. This inner strength is shown in the stubbornness of trying to make the best of the situation. However, despite building inner strength, the ordeal of living with chronic pain and its consequences was often overwhelming and created a feeling of hopelessness. The persons with chronic pain expressed that it is hard to live a life with severe chronic pain, and “one needs to be healthy to cope with being sick”.



## Domain 2: The person - Interacting with health care

The second domain explains that persons with chronic pain wish for changes in the primary care organization so they themselves do not have to be so adaptable and are treated with respect.

### **Category 2.1: Contact with primary care organization**

Interacting with primary care is a part of everyday life for persons with chronic pain. The primary care organization has a great impact on the individual. The amount of time it takes to get the right diagnosis, the right treatment, or an appointment with the right health care provider can lead to decreased trust in the primary care organization. The persons with chronic pain did not want others to have to go the same long and winding path through the health care system as they have done. Persons with chronic pain expressed a wish for more flexibility and increased *availability of primary care*. Proposals on how this can be achieved included by simplifying technology and diversifying the ways of contact. One example of a proposal to ease their everyday life was to simplify the way to apply for sick leave, for example making it possible to do it by phone instead of a physical meeting.

Persons with chronic pain also wish for more *continuity in care* in the primary care organization. Proposals included an easier way to book an appointment with their doctor, as well as a joint medical record system for all health care providers. Going to the same physician creates trust and a feeling of safety, and so the person does not have to adapt by telling their story repeatedly. A follow-up after an appointment or treatment is unfortunately rare but appreciated, since it can diminish the feeling of worry of being forgotten by the primary care organization.

*Interprofessional care* is appreciated but is seldom offered by the primary care organization. Persons with chronic pain say that they can only expect strictly medical treatment and that this leaves them with a feeling of hopelessness. If more professions were included within primary care, persons with chronic pain believe that the complexity of their pain would be seen in a different light. They consider that the primary caregivers would not just see them as a person with chronic pain but as a whole person.

*Digital tools as a complement*, for example a digital pain school, could be used to support the current treatment of chronic pain. Persons with chronic pain think this option could make the primary care organization more accessible. However, they are afraid it would become a replacement and not a complement to the physical appointment. Some worry that the digital tools may bias the clinical assessment in a negative way and that the health care personnel will forget the person in front of them and judge them by the information they received through the digital tools.

## Category 2.2: Treated with respect

The participants *wish for better partnership* and treatment when in contact with primary care. Some persons with chronic pain experience the primary care support as helpful and obliging, and feel they are being listened to and taken care of by their health care provider. Unfortunately, not all those with chronic pain have such an experience.

There is a wish *to be taken seriously* when seeking help for their pain, since not being taken seriously results in a feeling of frustration. Some persons feel that they are met with disbelief when expressing their pain. Their physician describes them as healthy in their medical record after they had reported their chronic pain during a medical appointment. Their subjective experience did not matter, and they felt frustration in situations when they were not listened to. Participants also spoke of judgemental attitudes from their health care provider, and that this influenced their treatment. Some have been told that they are afraid of working (work shy) or a drug abuser. That they had gotten their dose, but no other treatment options were discussed. Some persons who moved to Sweden from a foreign country sometimes prefer to visit doctors who also are from a foreign country, as they feel they are less judged by these doctors.

To improve the partnership between themselves and the health care provider, persons with chronic pain expressed the *need for a holistic view* from professionals. They wish for more equal health care where everyone is being treated with respect, not based on their symptoms, as well as with person-centred care. This would make it easier to build a partnership with their health care provider.

## Discussion

This report is a summary of the discussions at the workshop. It reflects the discussion of the 15 participants, but here we also reflect over the relation to theory and research done in the field.

The workshop highlighted the need for persons living with severe chronic pain to adapt and become experts in handling everyday life to ease the strain on both body and soul. Further, the material emphasizes the importance of a person with chronic pain needing to be strong and adaptable to be able to collaborate with the health care sector. Persons need support and encouragement from the surroundings through interaction with health care, and especially primary care. The adaptation required is a long process of learning, which could be more efficient with more support. The person needs to prioritize among daily activities, to adjust or reduce exercise and social activities, plan their chores, and include time to rest (1, 17). Like the findings in our report, other studies have shown that person living with chronic

pain handle everyday life by taking responsibility and enabling their own care (18, 19).

When interacting with health care, persons with chronic pain try to find their inner strength as a form of adaptability. An earlier interview study showed that stubbornness, strength and actively informing health care personnel was essential for health care interactions, and that having to produce this inner strength while ill was exhausting (18). Persons with chronic pain often needed to fight to receive care (18). The same behavior was identified in our workshop and presented in the category *taking charge of their everyday life*.

In our workshop, persons reported that they control their handling of everyday life by adapting with an optimistic mind-set, using creativity, decisiveness, determination, and visionary thinking. This is in line with persons with high self-efficacy. When managing chronic pain, incorporating self-efficacy is viewed as beneficial and valuable (20), in the context of dealing with pain and possible relief from pain. If a person has low confidence in their ability to perform a task, in this case managing their pain in their everyday life (i.e., low self-efficacy belief), the pain experience is worse, compared to persons with higher self-efficacy pain beliefs. There is evidence that pain-related disabilities could be less when persons have higher levels of self-efficacy, thus raising awareness about self-efficacy as an alternative in chronic pain treatment (21). Persons who experience pain as their worst enemy, feeling that it interferes with their autonomy and integrity, have a state of mind strongly associated with low pain-related self-efficacy (4). To avoid this state of mind and increase a person's self-efficacy could be important goals for health care during the rehabilitation process.

One method that could be used to improve pain-related self-efficacy is person-centered motivational interviewing. Health care professionals could in theory use this approach in the rehabilitation process to support a person's motivation and willingness for behavioral change. Results from a systematic review indicate that motivational interviewing increases adherence to treatment and possibly decreases pain (22), but there is a need for more research within this area.

Health care workers ought to be prepared to do a thorough assessment of persons dealing with chronic pain by listening to their subjective experience and being observant of objective signs (10). Some persons stated that it was important to be taken seriously, and not to be disbelieved. This has been shown to be of great importance, especially in the investigation of pain and for strengthening the partnership in the health care encounter (23). An aspect of person-centered care is to respect and acknowledge the experiences told by the person in front of you (11). The relationship with health care personnel, both at the first encounter and in future

interactions, can be negatively affected if a person with chronic pain is not taken seriously (24). However, a feeling of being supported could be intensified if health care workers inquire how the pain affects daily activities, relationships, work abilities etc. (25). Therefore, as requested by the participants of the workshop, using a holistic perspective in the interaction with and treatment of persons with chronic pain, would benefit both the persons with chronic pain receiving care and the health care personal (18, 26).

Persons with chronic pain perceive that preconception of their illness have a large influence when meeting primary care. They often feel judged, causing them to feel humiliated, and ignored because of their illness (18), which can intensify the anguish that comes with chronic pain (27). Health care personnel must be aware of the power they have to influence the suffering of these persons by believing their accounts of their pain and taking them seriously. Persons with chronic pain often have difficulties interacting with health care. For example, they are often asked to rate their pain using a scale (28), but they recognize that pain is very diverse and affects everyday life in so many more ways than can be easily summarized into one number. The experience is that health care workers rarely see the complexity and the dimension of their pain. They wish to be seen as experts of their own pain, for a holistic view, to build partnership and continuity in care. Small things like regular check-ups from health care via telephone could help the person dealing with chronic pain experience a greater feeling of power to take on their everyday life struggles (29). During our workshop, digital tools were presented as an example to support the contact with health care. The overall feedback was that these could be a good complement, if they did not replace physical meetings with primary care. Registered nurses working in primary care have earlier been described as providing good support for persons living with chronic pain; they showed empathy and were perceived as helpful, in contrast to physicians (29). The registered nurses had time to listen to their accounts of pain and thereby were a great emotional support (29), in line with participants of our workshop wanting a more holistic and person-centered care. Thus, health care personnel can improve the health care encounter by listening to patients (9).

Participants in the workshop represented different socioeconomic backgrounds and ethnicity, but we had no control of differences as the material was anonymous. As most of the participants (12 out of 15) identified as female, more participants identifying as male would have been desirable, but in society more women are living with chronic pain. The information given in the invitation was the same for all participants. All participants were recruited from patient organizations, which might affect the results as they were already engaging in handling and adapting their everyday life. Therefore, there is a risk that the discussion was affected by their interest in changing the organization of health care, being persons that already have made the journey to be able to adapt.

## Thoughts based on the workshop material

Persons living with severe chronic pain must adapt and become experts in handling everyday life to ease the strain on both body and soul. This also includes the interaction with health care. There is a great responsibility for persons themselves, but the health care personnel should aim to see the whole person in front of them, and not just the symptoms. This is one way to ease the burden for the patients, and with a person-centered approach within the care this can be achievable. By implementing and practicing person-centered care, primary care could offer persons with chronic pain the support they need to develop their adaptability. Health care workers need more knowledge to guide and support the journey for these persons living with chronic pain, to make it smoother and shorter.

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