



Communication

What Cluster Headache Patients Would Like Their Relatives to Know: Results from a Qualitative Study

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Abstract: Many patients with cluster headaches report that their relatives do not understand what they are going through. This qualitative study aimed to collect patients' recommendations and wishes on how others should respond to those suffering from cluster headaches. We recruited 22 patients with episodic or chronic cluster headaches for this cross-sectional study. They responded to seven questions that assessed the disease's impact on their relationships with relatives and their wishes for others' behaviour towards them. Seven recommendations for relatives emerged: (i) withdraw during attacks, (ii) respect post-ictal exhaustion, (iii) do not insist on discussing the disorder, (iv) help the patient to lead a "normal" life, (v) support preserving social contacts, (vi) show being aware of the disease severity, and (vii) expect the disease to take up space in patients' lives and minds. Two recommendations for the interictal period indicate avoidance, which is considered a negative coping strategy. Conversely, the suggestion to support preserving social contacts might mean confronting the disease, which is likely associated with more favourable outcomes. Still, adhering to all patients' requests might increase suffering instead of reducing it. Thus, further research is needed to develop strategies suited to improve well-being.

Keywords: burden of disease; pain; coping; partner communication; avoidance; emotion regulation



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1. Introduction

Cluster headache attacks are difficult to bear due to intense pain, disrupted sleep, and fear and anxiety [1,2]. More than that, the disorder often reverberates in everyday life, resulting in difficulties in the workplace and private life. The condition does not permit patients to fulfil their responsibilities as they used to and live up to their own and others' expectations.

Unsurprisingly, many affected persons feel misunderstood by family, friends, colleagues, and employers. Some recall relationship conflicts and break-ups that weigh heavily on their quality of life [3,4].

Many patients are reluctant to speak with others about their disorder and the associated burden [1,3]. However, communicating indisposition might help cushion the impact of the disease. Indeed, studies investigating cancer patients suggest that family members are a potential source of strength and generally want to support affected persons, but often do not know what to do [5–7].

Particularly at the onset of cluster headache, many patients might not know how their social circle should best behave and how the disease will influence their lives. This study collected patients' viewpoints and their wishes on how others should respond to those suffering from cluster headache attacks. The objective is to generate data from which discussions with patients and relatives about changing needs can draw.

2. Materials and Methods

This article reports the primary analysis of data collected specifically for this study.

2.1. Participants

Adults (≥ 18 years) diagnosed with cluster headache at the headache outpatient clinic at the University Hospital Zurich were eligible to enrol. Participants were informed about the study through a flyer. They were recruited specifically for this research project from October 2022 to March 2023.

We had not aimed for a specific number of participants. Hence, the available data determined the sample size.

2.2. Design

We conducted this observational study at the University Hospital Zurich, Switzerland. All participants were invited to provide free text responses to a questionnaire.

The questionnaire comprised the following items.

1. How should your family, friends, and acquaintances behave during an attack? Can they support you (if yes, how?), or would you prefer if they withdrew?
2. How should your family, friends, and acquaintances behave immediately after an attack? Do you require rest or care?
3. How can your family, friends, and acquaintances support you between the attacks?
4. How did your relationship with family, friends, and acquaintances change since the onset of the disorder?
5. Have you changed since the onset of the cluster headache? Has the disease affected you and your life (if so, how?)?
6. Is there anything you would like your family to know about the disease?
7. Is there anything you want to tell the families of other people with cluster headache?
8. We complemented these data with the following information from the patient files: age, sex, disease duration, and precise diagnosis (episodic vs. chronic cluster headache).

2.3. Data Analysis

The analysis of the qualitative data followed the SAMMSA approach published by Macdonald and co-workers [8]. To that end, two authors (PS and HP) first grouped patients' answers into micro-themes and then into meso-themes based on commonalities among the micro-themes. Then, we composed a narrative synthesis based on the meso-themes.

We report categorical variables as absolute and relative frequencies and continuous variables as means and standard deviation with their median. Missing data are indicated as "not reported" (n.r.).

3. Results

We invited 105 patients to participate in the study. Twenty-two participants were enrolled (22/105, 21.0%) and completed the questionnaire; 10 were female (10/22, 45.5%), and 10 suffered from chronic cluster headache (10/22, 45.5%). Reasons for non-participation were not assessed. Their average age was 51 ± 15 years (minimum 21, maximum 76, median 49.5 years); the average disease duration was 15 ± 14 years (minimum 1, maximum 42, median 8.0 years; 1 n.r.). See Table 1 for further details.

Table 1. Participants' demographic data; n.r.—not reported.

Number	Age in Years	Sex	Disease Duration in Years	Episodic vs. Chronic
1	21	female	3	chronic
2	76	female	6	chronic
3	57	male	n.r.	episodic
4	45	female	40	episodic

Table 1. Cont.

Number	Age in Years	Sex	Disease Duration in Years	Episodic vs. Chronic
5	66	male	42	chronic
6	48	male	20	chronic
7	45	male	4	episodic
8	74	male	13	chronic
9	48	male	4	episodic
10	31	female	7	episodic
11	46	female	8	chronic
12	65	female	14	episodic
13	51	female	9	episodic
14	35	female	2	episodic
15	54	male	32	chronic
16	66	male	40	episodic
17	29	male	3	chronic
18	63	male	38	episodic
19	61	female	3	chronic
20	33	male	6	chronic
21	57	male	1	episodic
22	45	female	13	episodic

One patient's (P1) diagnosis changed from chronic cluster headache to paroxysmal hemicrania after the invitation to participate had been sent.

3.1. Question 1: Support during the Attacks

Nineteen participants commented on the meso-theme "presence or absence of other people during the attack", and fifteen preferred being alone. However, two (P12 and P19) added that they would like someone within earshot (e.g., in another room), and another two (P13 and P14) enjoyed the presence of other people.

One person (P16) stated they did not want to talk during the attack; three (P2, P4, and P15) wrote they did not want to be touched. Conversely, one person (P14) liked her partner to massage her arms; however, it was unclear if she referred to the ictal period.

Regarding the meso-theme "others' active support", three (P2, P3, and P16) said they could not be supported during the attack, and one person (P8) wrote that he did not need any support. One (P22) said she appreciated her relatives bringing acute medication. One (P17) recommended not informing them about an upcoming attack, as they could not help.

3.2. Question 2: Support after the Attacks

Several participants contributed to the meso-theme "relaxing/recovering". Six (P1, P4, P12, P13, P15, and P22) expressed the need to rest or sleep, thirteen (P2, P3, P9, P10, P13, P14, P15, P17, P18, P19, P20, P21, and P22) preferred a quiet room, and two (P7 and P17) said they were temporarily cognitively limited after an attack. One person (P1) added that she enjoyed breathing fresh air.

Concerning the theme "interaction with others", eight (P2, P5, P6, P7, P8, P16, P17, and P21) wanted the people around them to behave as if no attack had occurred. Two (P4 and P13) liked others to be close; two (P12 and P20) did not.

3.3. Question 3: Support in between the Attacks

Eleven participants (P5, P6, P7, P8, P9, P12, P18, P19, P20, P21, and P22) indicated that support is not possible or wanted. However, some appreciated others' "practical support": Two (P1 and P4) were grateful for relatives helping them take medication and see doctors, and two (P4 and P13) were happy that their family showed some understanding for their suffering.

A further theme was “establishing normality”. Two (P4 and P11) liked that their families established some normality between the attacks; one (P15) found being distracted from the disease positive. Three (P2, P3, and P17) appreciated relatives talking with them about their condition; however, two (P15 and P16) did not. Moreover, four participants (P1, P2, P14, and P15) mentioned that families could provide support by taking the triggers of an attack seriously and avoiding them.

3.4. Question 4: Changes in the Relationships

Eight (P3, P7, P10, P12, P16, P19, P20, and P22) participants did not report any changes in their relationship with their family. Nevertheless, a common theme was the loss of social contacts that nine participants (P2, P4, P9, P11, P12, P13, P14, P15, and P17) had experienced. Four (P1, P2, P8, and P15) added that they had had to cancel appointments on short notice or that they had to be cautious at these events. Three (P11, P12, and P17) reported that the disease had led to the end of a romantic relationship. Four (P2, P4, P15, and P18) found that anxiety, irritability, bad temper, and nervousness complicated their relationship with others.

Another theme was changes in others’ behaviour towards the patients. Three (P1, P5, and P6) felt their family worried about them; five (P10, P11, P13, P15, and P17) found that family members did not understand what they were going through.

Another theme was how relatives deal with the disease. Three participants (P2, P11, and P21) reported that relatives had difficulties handling the situation, with some withdrawing from the participants for being unable to cope with or accept the disease. Conversely, one (P5) found that their relatives had learned to cope with the disease.

3.5. Question 5: Changes in the Patients Themselves

Only two participants (P5 and P16) reported that the disease had not changed them. One important theme was patients’ reduced well-being. Eight (P2, P8, P12, P13, P17, P19, P20, and P21) reported suffering from depression, psychological distress, or fatigue. Five (P2, P3, P12, P18, and P19) indicated a darkened mood, four (P3, P7, P12, and P13) were anxious, and one (P2) felt helpless.

Another theme was “functioning”. Seven participants (P1, P9, P11, P13, P15, P17, and P20) reported difficulties at work, and six (P1, P10, P15, P17, P19, and P20) felt that the disease negatively affected their leisure time because they had to cancel on short notice, could not make plans, could not attend some events, or had to give up their hobbies.

A third meso-theme was the “disease-centeredness” of life. Two patients (P1 and P19) said they had to consider the bouts when planning a vacation, another (P14) said he could not leave the house without acute medication, and another (P17) worried about the disability pension. He (P17) also reported that appointments with physicians had become a part of his life.

3.6. Question 6: Information for One’s Own Family

Only two participants (P16 and P20) believed there is nothing to tell one’s family. One meso-theme was the importance of informed family members. Thirteen (P2, P3, P5, P8, P9, P10, P12, P13, P15, P17, P18, P19, and P21) wanted their family to have some knowledge about the disease; two (P14 and P17) wanted them to know how well the acute medication functions and one (P10) wanted them to know how to behave during the attack. However, only three (P2, P4, and P22) wanted support and compassion.

Another theme was the disease severity, which some patients wanted their relatives to bear in mind. Two (P9 and P11) emphasized the wish to die during the attacks, and one (P1) wanted them to know that the disease did not allow her to make plans.

3.7. Question 7: Information for Others’ Families

Several answers to this question centred on the theme “support”. Seven (P9, P10, P13, P14, P15, P17, and P22) advised patience and understanding, and two (P13 and P17) advised

to keep in mind that recovery after the attack takes some time; however, two (P15, P17) cautioned not to pity the patient. Two (P2 and P15) recommended being open about the disease, and another one (P2) suggested being optimistic. Still, another participant (P15) recommended talking about the disease only if the patient wants to and treating patients as “normally” as possible (P19). One person (P6) suggested seeing a specialist, and another (P21) cautioned against unhelpful physicians at the emergency department.

Another meso-theme was the “disease severity”. Three participants (P13, P16, and P22) wanted their family members to know how painful the attacks were.

3.8. Narrative Synthesis

Patients must confront the attacks by themselves. The presence of others is not only unhelpful but also unwanted—only a few wish to have another person within earshot. Directly after the attack, the patients are exhausted and usually prefer not to interact.

During the interictal period, many do not want to discuss or think about the disease, but appreciate a distraction. Many do not want active support from family members; however, they often are grateful if they bear in mind the severity of the disease, help to live a “normal” life beyond the illness and show some understanding. Frequently, the condition becomes a central part of their own and their families’ lives.

Many feel that the disorder interferes with normal functioning and well-being, manifesting as difficulties at work and in private life. The reason is that besides the need to recover after attacks, many are anxious, irritable, badly tempered, or nervous.

4. Discussion

This study collected information about patients’ perceptions of cluster headache and their wishes for how others should respond to the attacks, the disease, and the patients themselves. The narrative synthesis shows an exhausting disorder characterized by extreme discomfort and pain during the attacks, and anxiety, irritability, and reduced capacity to work and interact with others during the interictal period.

Seven recommendations for relatives emerge from the data. These are: (i) withdraw during attacks, (ii) respect post-ictal exhaustion, (iii) do not insist on discussing the disorder, (iv) help lead a “normal” life, (v) support preserving social contacts, (vi) show awareness of the disease severity, and (vii) expect the disease to take up space in patients’ lives and minds.

The first two recommendations address the peri-ictal period and express the desire to be left alone. While one reason for that wish could be that the attacks are exhausting, another might be that patients attempt to control or suppress some aggression during the attacks [9].

Many patients describe the pain as localized and sharp [10] and some even liken it to a knife stuck in the head [11]. Several authors thus concluded that this pain feels “escapable” [12] and hypothesized that it is irrelevant for the human brain whether a knife is stuck in the head or if it only feels like there is one: in either case, the affected person engages in an involuntary defence reaction that may feel and manifest like aggression [12,13]. Hence, not seeing another person may prevent directing aggression against them.

If we interpret the behaviour during the attacks as due to feeling under attack, we should consider that this feeling might also drive the interictal behaviour. The unconscious response might not end when the pain does.

Having become a victim of violence often leads to emotional distress [14]. One possible consequence of repeated exposure is a maladaptive coping mechanism called the “stress or distress pathway” [15]. It manifests—amongst others—as emotional distress and externalizing difficulties. Some participants’ irritability, bad temper, and nervousness might correspond to these phenomena.

Two recommendations addressing the interictal period (iii and iv) reflect another type of negative coping that consists primarily of avoidance by pretending normality. It, too, has been found in violence victims, even in the absence of repeated victimization; it

implies that the controllability of the headache is perceived as low [15]. In this study, one common type of avoidance was not wanting to discuss the disorder with families and friends—a behaviour an earlier study reported, too [1].

Fear is likely one significant driving force behind the aversion to speak about the attacks [1]. As Lethem and co-workers pointed out, fear of pain can lead to confrontation or avoidance [16]; that avoidance could increase the disease severity, meaning that confronting the disease is recommended. Asking relatives to help preserve social contacts (recommendation v) may indicate an attempt at such confrontation. However, although many patients attempt to gain control over their disorder, few feel they succeed [1,17].

We do not know if unconscious feelings of being a victim of violence motivate the participants' coping styles. However, independently from their cause, research indicates that negative coping strategies are “negative” or “unhealthy” because they do not promote well-being; avoidance is associated with increased stress, anxiety, depressive symptoms, and reduced satisfaction with life [18,19].

This article highlights that negative coping strategies are prevalent among patients with cluster headache. This finding provides a potential explanation for the tremendous interictal burden of the disorder. Furthermore, it suggests that educating patients on coping strategies may help reduce the burden. However, we require more research on delivering such education and its impact on the disease burden.

Our initial plan was to forward our findings to patients' relatives to help them adapt their relationship styles. However, the consequences of being treated as wished are unknown—following patients' recommendations might harm instead of alleviating distress. Thus, our findings indicate a need to study the effect of different coping strategies on well-being in patients with cluster headache. Moreover, it might be fruitful to understand where and how patients who “confront” the disease do so.

Limitations

Although we invited more than 100 patients, only some participated in the study. Moreover, women seemed overrepresented, given that cluster headache currently affects about twice as many men as women [20]. Hence, a unit non-response error cannot be excluded. Moreover, a further potential source of bias is that we did not solely include participants in the active period. In addition, the study design did not allow us to ask participants to rephrase or specify their answers if we were unsure that we understood them correctly. However, given that many of the replies strongly resembled each other, we believe the findings can be generalized.

5. Conclusions

This study collected patients' views about and needs within their relationships with their next of kin. The findings underpinned the notion of a difficult-to-deal-with disease.

Several common themes emerged in the questionnaires that could be condensed into seven recommendations for patients' relatives. These are: (i) withdraw during attacks, (ii) respect post-ictal exhaustion, (iii) do not insist on discussing the disorder, (iv) help the patient to lead a “normal” life, (v) support preserving social contacts, (vi) show awareness of the disease severity, and (vii) expect the disease to take up space in patients' lives and minds.

Several of the patient's wishes for how others should behave implicate negative coping strategies that might fail to promote well-being. Hence, we recommend researching effective coping strategies in patients with cluster headache.

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