



Original Article

Understanding Experiences of Headache-Sufferers Attending Emergency Departments Through Photovoice

Lynette D. Krebs¹, Nicole Hill^{1,2}, Nicholas Lesyk¹ , Cristina Villa-Roel¹ and Brian H. Rowe^{1,3} 

¹Department of Emergency Medicine, Faculty of Medicine & Dentistry, College of Health Sciences, Edmonton, Canada, ²Department of Sociology, Faculty of Arts, All at the University of Alberta in Edmonton, Edmonton, AB, Canada and ³School of Public Health, College of Health Sciences, All at the University of Alberta in Edmonton, AB, Canada

ABSTRACT: Objective: Our aim was to explore the experiences of individuals receiving emergency department (ED) care for acute headaches. **Background:** Patients with headache exacerbations commonly present to EDs. This study explored the experiences of adult patients during the exacerbation period, specifically using photovoice. **Methods:** Recruited from two urban EDs in Alberta, Canada, participants with primary headaches took photographs over 3–4 weeks and subsequently completed a 60–90 minute, one-on-one, in-person photo-elicitation interview. Interviews were audio recorded, transcribed and thematically analyzed alongside photographs. **Results:** Eight participants (six women) completed the study. The average age was 42 years (standard deviation: 16). Five themes emerged: (1) the struggle for legitimacy in light of the invisibility of their condition; (2) the importance of hope, hopelessness and fear in the day-to-day life of participants; (3) the importance of agency and becoming “your own advocate”; (4) the struggle to be and be seen as themselves despite the encroachment of their headaches; and (5) the realities of “good” and “bad” care in the ED. Participants highlighted examples of good care, specifically when they felt seen and believed. Additionally, some expressed the acute care space itself being a beacon of hope in the midst of their crisis. Others felt dismissed because providers “know it’s not life or death.” **Conclusions:** This study highlighted the substantial emotional impact that primary headaches have on the lives of participants, particularly during times of exacerbation and while seeking acute care. This provides insight for acute care settings and practitioners on how to effectively engage with this population.

RÉSUMÉ : Mieux comprendre au moyen de la démarche photovoice les expériences d’individus qui se présentent aux services d’urgence en raison de maux de tête. Objectif : Notre but est ici d’explorer les expériences des personnes qui reçoivent des soins aux urgences pour des maux de tête. **Contexte :** Les patients atteints de maux de tête exacerbés se présentent souvent aux urgences. Pour cela, nous avons cherché à mieux comprendre les expériences de patients adultes pendant leur période d’exacerbation en recourant spécifiquement à la démarche dite photovoice. **Méthodes :** Recrutés dans deux services urbains d’urgence de l’Alberta (Canada), des participants souffrant de maux de tête primaires se sont pris en photo pendant une période de 3 à 4 semaines ; ils ont ensuite participé à un entretien individuel de 60 à 90 minutes recourant à la méthode de la photo-élicitation. Ces entretiens ont été enregistrés, transcrits et analysés thématiquement parallèlement avec les photographies. **Résultats :** Au total, 8 participants (six femmes) ont terminé l’étude. Leur âge moyen était de 42 ans (écart-type : 16). Cinq thèmes ont émergé : 1) la lutte pour la légitimité à la lumière de l’invisibilité de leur état ; 2) l’importance de l’espoir, du désespoir et de la peur dans leur vie quotidienne ; 3) l’importance de la capacité d’agir (agency) et de devenir « son propre porte-parole » ; 4) la lutte pour exister et pour être vu comme soi-même malgré l’empiètement de leurs maux de tête ; et 5) la réalité des « bons » et des « mauvais » soins prodigués dans les services d’urgence. À cet égard, les participants ont souligné des exemples de bons soins, en particulier lorsqu’ils se sentaient vus et crus. En outre, certains ont indiqué que les espaces de soins aigus constituaient en soi une lueur d’espoir au cours de leur crise. En revanche, d’autres se sont sentis rejetés parce que les prestataires de soins de santé « sont d’avis qu’il ne s’agit pas d’une question de vie ou de mort ». **Conclusions :** Cette étude a mis en évidence l’impact émotionnel considérable des maux de tête primaires sur la vie des participants à cette étude, en particulier pendant leurs périodes d’exacerbation et lorsqu’ils sont à la recherche de soins aigus. Cela permet aux établissements de santé, en contexte de soins aigus, et aux praticiens d’avoir une meilleure idée de la manière dont ils peuvent intervenir efficacement auprès de cette population.

Keywords: Headache; emergency medicine; migraine; photovoice; qualitative methods

(Received 6 March 2024; final revisions submitted 22 July 2024; date of acceptance 23 July 2024)

Corresponding author: Brian H. Rowe; Email: browe@ualberta.ca

Cite this article: Krebs LD, Hill N, Lesyk N, Villa-Roel C, and Rowe BH. Understanding Experiences of Headache-Sufferers Attending Emergency Departments Through Photovoice. *The Canadian Journal of Neurological Sciences*, <https://doi.org/10.1017/cjn.2024.286>

© The Author(s), 2024. Published by Cambridge University Press on behalf of Canadian Neurological Sciences Federation. This is an Open Access article, distributed under the terms of the Creative Commons Attribution licence (<http://creativecommons.org/licenses/by/4.0/>), which permits unrestricted re-use, distribution and reproduction, provided the original article is properly cited.

Introduction

Patients experiencing primary headaches (e.g., exacerbations of chronic migraine, tension and/or cluster headaches) commonly present to the emergency department (ED).¹⁻³ Qualitative studies exploring the lived experiences of individuals suffering with non-acute headaches, including migraines, consistently highlight the substantial impact that their condition has on their physical, relational and emotional health.⁴⁻⁶ Participants in other studies described the experience as “handling the beast”⁷ and reshaping their lives around their condition.⁶ Studies reported participants’ fears over possible underlying conditions as well as how their invisible condition would be perceived.^{6,8-10} Some studies reported specific challenges in the clinical environment.^{4,10} For example, participants struggled when they perceived limited support, or even doubt and questioning, from their clinical care team. These interactions compounded the feeling of suffering alone and contributed to incomplete treatment⁴ and feelings of hopelessness.¹¹

To our knowledge, the exacerbation period specifically and ED care-related experiences have not been previously investigated. This study seeks to fill this gap by using the photovoice method, which falls under the participatory action research framework. By using the photovoice method, we set out to empower patients to externalize their often isolated experience of headache exacerbations^{9,12} and provide clinicians and healthcare administrators an insider’s perspective of their experience with headache exacerbations.

Method

This study was conducted as part of a larger mixed methods study exploring care expectations, experiences and management of patients presenting to the ED with primary headaches. Recruitment was undertaken at two urban EDs in Edmonton, Canada, from September 2017 to November 2018.

Participant identification and recruitment

Using consecutive sampling, a trained research nurse approached ED patients (≥ 17 years of age) with the presenting complaint of headache and a Canadian Triage Acuity Scale score of 3 (urgent) to 5 (non-urgent).¹³ Only patients who had a primary migraine headache, as confirmed by their treating physicians, were eligible for participation. Patients were excluded if they could not communicate sufficiently well in English or were deemed by their treating physician to be unable to consent.

Participants in the larger study were asked about their willingness to take part in the photovoice sub-study. To be eligible, participants needed to have access to their own camera and agree to engage in a one-on-one, face-to-face photo-elicitation interview (PEI). Those who provided consent while in the ED were contacted by phone or email within 1–2 days of discharge with additional study details.

Data collection

Photovoice provides the opportunity for participants to visually capture their exacerbation experience and subsequently, to narrate their experience through PEI and share it with those who make decisions relevant to their care (e.g., clinicians, administrators).^{14,15}

Participants were given 3–4 weeks to take up to 15 photographs representing their experience, specifically focusing on their exacerbation and ED care experience. Photovoice facilitators

(LK, NH; both with qualitative health research expertise) provided support when requested. Both facilitators approached the study as an opportunity for the co-creation of knowledge and were informed by the theoretical underpinnings of photovoice. Photographs were submitted via REDCap, a secure data collection platform (Vanderbilt University; Nashville, TN, USA). Subsequently, in-person, semi-structured PEIs were scheduled. Interviews were one-on-one, lasted 60–90 minutes and took place either at the research office or participant’s home.

Photographs were printed and used as the basis of the PEI, which followed the SHOWeD method.¹⁶ This method asks the following questions for each photograph: What do you *See* here? What is really *Happening* here? How does this relate to *Our* lives? *Why* does this situation, concern or strength *Exist*? What can we *Do* about it? Utilizing these questions as the basis of discussion allowed interviewers to understand what was physically pictured in each photograph as well as the experience being represented, along with the meaning it held for the participant. Ultimately, the SHOWeD method also allowed for the identification of any actions participants saw as relevant to altering or improving their experience. For interviews where the ED experience did not feature heavily in the photographs, several probes addressed the ED experience.

Interviews were audio recorded and transcribed. Frequent discussions about the interviews, including debriefs, occurred throughout the study. Field notes were maintained.

Data analysis

Transcripts were reviewed and cleaned (LK, NH). The analysis employed an inductive approach.¹⁷ Close reading and rereading of the transcripts, alongside the photographs, were undertaken.¹⁸ An “open coding” process was employed.¹⁹ Following the reading and rereading of transcripts, a discussion of emerging ideas was undertaken, and a preliminary understanding of the codes and analytic framework was established. The analysis was continued by NH, followed by additional discussions to refine codes and arrive at a consensus on how best to cluster the codes under themes and which photographs best illustrated each theme.

Subsequently, participants were asked to review the themes and any photographs and quotations that had been selected from their data. Once the analysis had been confirmed, a knowledge translation activity in the form of a gallery exhibit was created to display participants’ photographs and explanations of their art.

Ethics

Ethics approval was obtained (University of Alberta, Health Research Ethics Board Pro00067782). Written informed consent was obtained from each participant, which included permission to utilize participants’ photographs.

Results

Recruitment is summarized in Figure 1. Of the 85 patients participating in the mixed methods study, 76 (89%) were approached about the photovoice sub-study. Thirty-three (43%) agreed to participate. Following ED enrollment, 1 participant was identified as a screen fail, 4 participants withdrew due to worsening health or insufficient time and 20 participants were lost to follow-up. For all but one of them, this loss to follow-up occurred prior to photograph submission. Eight participants (identified as P 1–8) completed the study (8/33, 24%). Six identified as female, and the average age was 42 years (standard deviation [SD]: 16; range:

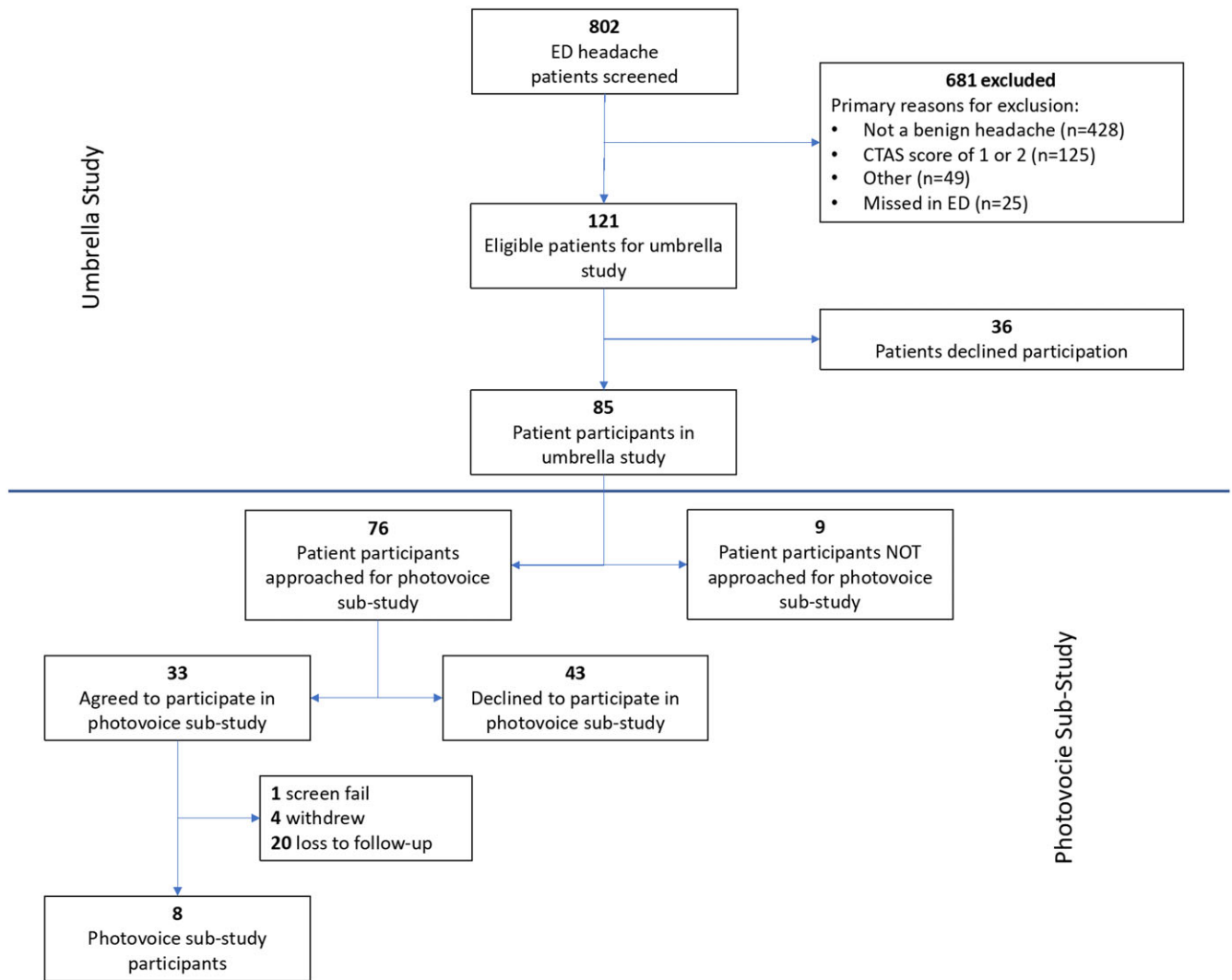


Figure 1. Umbrella study and photovoice sub-study study flow diagram.

19–62). Seventy photographs were submitted, ranging from 3 to 15 photographs per participant. Interview length ranged from 30 minutes to 1 hour 49 minutes. Thematic analysis revealed five themes.

Theme 1. “It’s hard ‘cause it’s an illness you can’t see”: the significance of legitimacy

Many participants struggled to have their headaches taken seriously. This struggle for legitimacy permeated all their relationships: work, friends, family and health care. Without visible signs of illness, such as being “bandaged and bleeding” (P3), a participant reflected: “I think some people think not that I am faking it, but I am over-exaggerating a headache” (P8). Other participants felt judged and worried that others would think less of them when they needed accommodation, for example, sick time from work. The search for legitimacy could be complicated by a lack of medical diagnosis, which could be invoked to explain symptoms.

For some participants, engaging with the acute care system offered the legitimacy they sought. Figure 2 was taken by a participant prior to enrolling in the study. This participant had sent

the photograph to her coworkers to “prove” that she was really at the ED. Receiving ED treatment added legitimacy to her symptoms – it was “almost like . . . making it visible” (P8).

Some participants’ struggle for legitimacy continued at numerous points within the ED care process. At triage, some participants felt the invisibility of their symptoms led staff to underestimate symptom severity. One participant stated, “there’s been numerous times where I’ve overheard nurses at the triage desk be like, ‘oh, that’s just a headache, they can wait’” (P4). Struggling for legitimacy extended to some physician interactions, as one participant shared that her physician made her feel that her chronic, recurring headache condition was “not real” (P8). This tension in physician interactions influenced patients’ medication access. One participant was told by a care provider that because they “can’t see the pain, [they’re] hesitant to treat” (P4).

When participants were able to get a diagnosis that could explain their pain and suffering, they felt this gave them legitimacy and credibility as well as emotional relief. One participant explained the feeling of finally receiving a diagnosis like, “oh! I *do* have something wrong with me . . . it gave me this weird sense of *I’m not manifesting this in my head, I’m not making this up*” (P3).



Figure 2. Participant getting IV medications in the emergency department.

Theme 2. The significance of hope, hopelessness and fear

Participants discussed a closely interrelated triad of emotions that played significant roles in their experiences: hope, hopelessness and fear.

“Light at the end of the tunnel”: the significance of hope

For some participants, the possibility of new treatments, seeing new doctors, referrals to specialists and even the ED itself offered hope that reducing their suffering might be possible. From a generalized “hope that one day they’ll be able to help people like me” (P8) to the “huge relief” that accompanied a specialist referral, hope played a central role in participants’ experiences.

One participant explained that when experiencing exacerbations, he felt like a “broken ship,” but arriving at the ED gave him hope that “someone is gonna help you put the ship back together” (P6). For some participants, physicians buoyed their hopes by reminding them that their current suffering was temporary. One participant explained that during a headache, “you’re in that dark room . . . you’re trapped, but there’s always light at the end of the tunnel” (P5) (Figure 3).

“The lowest of the low”: the significance of becoming hopeless

During exacerbations, hopelessness often set in, making participants question if they would ever feel better, particularly when headaches persisted for years (sometimes decades) and felt like “a never-ending battle” (P4).

Presenting to the ED was a daunting prospect, given its abounding triggers (e.g., movement, bright lights, noises, etc.), but when participants reached “the lowest of the low,” they went in,



Figure 3. The dark room of the headache with light at the end of the darkness.



Figure 4. Participant's swollen wrist with hospital ID bracelet in the emergency department.

desperate for relief. One participant described her experience of going to the ED and finding no relief. She said,

you're feeling like, when you go to the hospital, that it's like, 'kay, finally they're gonna drug me up, I'm gonna lay there and then I'm gonna get rid of this migraine . . . and then it's like, they can't even get rid of it? You just feel so hopeless . . . how am I ever gonna get rid of it?' (P2)

For another participant, going to the ED “got [her] hopes up,” but when symptoms remained unbearable, she questioned, “why did I do this in the first place? . . . What is really the point of going out and searching for help at this point?” (P8). These same doubts were mirrored across healthcare interactions and levels of specialization when participants left “empty-handed” (P4). Figure 4 was taken by a participant in a moment of hopelessness. She explains that the photo shows her ED identification bracelet becoming tight due to the volume of IV solution she had received. At this moment, she remembered thinking, “I don't think I can do this, I just wanna ask them to take it out . . . Maybe I should fake it and say I'm fine . . . I don't care anymore, I just wanna go home” (P8).

AQ2

At times, interactions with healthcare providers were a source of hopelessness. One participant's physician was “frustrated that nothing was working” (P8) after numerous treatment attempts. Another participant was surprised to be prescribed methadone for her symptoms and asked about her understanding that it was used to treat addiction, not migraines. Her physician replied, “well, we use it on end-of-life cancer patients too.” The participant reflected, “I never left feeling so hopeless in my life before” (P4).

“I thought I was dying”: the significance of living in fear

For many participants, the intensity of their symptoms felt like they “could be crushed at any time” (P5) or were facing “an invisible power [that] is trying to murder you” (P6) (Figure 5). In addition to fearing their intense symptoms, participants frequently relied on



Figure 5. Red pepper in vice representing the feeling of being crushed by symptoms.



Figure 6. Wrapped baby statue representing peacefulness of the MRI.

care providers to investigate or rule out potentially life-threatening conditions.

Consequently, availability of diagnostic imaging in the ED played a significant role in assuaging fears. Getting a scan could “take the pressure off” after participants “imagin[ed] terrible things” (P3). One participant submitted Figure 6, showing a contented, peaceful statue of a baby, which represented the experience of undergoing an MRI. He explained,

when you're in it, that's what you feel... when you're in the treatment area... you're being taken care of... you're at peace... regardless of what the outcome is, at least action's taken. (P5)

Healthcare institutions and providers were seen, in some respects, as a haven from uncertainty. For others, the ED made them feel anxious and afraid, which further increased their stress, especially if they had to go alone.

Participants also worried about how headaches impacted their quality of life. All participants described headaches causing them to miss work, take leaves or access disability benefits. Some worried about the impression these absences gave employers or about the financial implications. Trigger avoidance and management were another source of constant fear, as participants described diligently restricting their activities and environments. Sometimes trigger avoidance was impossible, which was frustrating and contributed to the “vicious cycle” of stress and trigger management (P4).

Theme 3. “You have to be your own advocate”: the significance of agency

Agency was significant for participants, from their strategies to prevent and cope with headaches to being active members of their care team.

Many participants focused on headache prevention, including making significant lifestyle changes and vigilantly monitoring symptoms in an effort to “get ahead of the game and kinda cut off

the migraine before it starts” (P4). Especially where medication costs were a challenge, limiting drug use was important; one participant discussed taking great lengths to “save her from using a pill” (P2).

During exacerbation, participants employed pain-minimizing strategies, including breathing exercises and positive thinking. They also advocated for their needs at home. Figure 7 depicts a note left by a participant for his roommates in an attempt to minimize interactions during an exacerbation.

Participants advocated for themselves by acquiring knowledge about their headaches, researching common triggers/interventions and developing their own experiential knowledge. This knowledge informed their day-to-day living as well as their interactions with healthcare providers. One participant explained, “I have to know for *my* health what's best for me... It's tiresome... you're always battling to make sure that it's the number one priority” (P4). For some participants, developing this knowledge helped them to regain some sense of control over their health, although they experienced frustration when it was dismissed by care providers.

Theme 4. “This isn't who I am”: the significance of identity

Participants fought against headaches' power to define them and their lives, both during an exacerbation and not, within the health system and outside of it. Figure 8 shows a participant laid up in the ED with a basin between her legs to catch vomit. Participants fought to be more than this representation, both to themselves and to others.

Participants' day-to-day lives and larger goals were defined by their headaches. One participant stated, “it just like, completely consumes me... it's just like I'm not who I usually am whenever I have a migraine” (P4). Even when not experiencing an active headache, headaches encroached on participants' lives. Participants lamented having “to plan life around migraines” (P1). One participant explained,



Figure 7. Participant's "leave me alone" sign in a shared living space.



Figure 8. Participant in the emergency department with a basin to catch emesis.

it impacts everything . . . countless plans cancelled, tons of work missed. I'm afraid to even make plans sometimes, 'cause it's like 'what if?' It ruins vacations, even just going away for the week, I always have [a headache], so it's really not fun. (P2)

Overwhelmingly, participants communicated that "it's hard to live like this" (P4). The inevitability of canceled plans and

accompanying emotions led one participant to submit Figure 9, saying "this basically represents my social life . . . non-existent because I have migraines like every day . . . empty calendar, no social life, no work half the time, just nothing. No life . . ." (P2). This empty life led one participant to wonder, "am I able to live my life to the fullest with what I have?" (P8).

Many participants wanted connection but also felt like a burden. Consequently, participants reported feeling "alone" (P4) and "los[ing] a lot of friends" (P1). One participant described trying to maintain her sense of self, saying "I don't want my life to be surrounded by the headaches, I want my life to be at the centre, the headaches just to be like on the outside" (P8).

Theme 5. "Good" and "bad" care: the significance of caring

Participants described the significance of their ED care and its impact on them, both when it was "good" and "bad." Multiple participants identified that the quality of care varied based on which physician they saw. For example,

sometimes you get a very compassionate doctor that knows exactly what you're going through and they treat you and they treat you well, and then sometimes you get somebody who just doesn't get it, and you sit there and you suffer and you go home being just as bad off as you were when you got there. (P4)

Although almost all of the participants had concerns about elements of their care, they also insisted that healthcare providers were "amazing" and generally doing a good job (sometimes in difficult circumstances, such as overburdened EDs).

Good care

Good care often began with the demeanor of the staff. "Polite," "caring," "kind" or "friendly" staff were described positively. Fundamentally, when participants felt that they were noticed as a person or that their unmet needs were noticed, they felt well cared for. These pleasant exchanges reduced participants' stress. Simple gestures



Figure 9. Participant's empty calendar devoid of plans to leave room for their headaches.

like trying to make patients comfortable by dimming lights, attempting to place them in quieter areas or ensuring proximity to a bathroom were appreciated. One participant said, “they’re trying their best to accommodate me . . . they may not be doing the best ideas or stuff [referring to accommodations that weren’t effective] . . . but they’re trying” (P8).

Good care providers were perceived as compassionate and sensitive to participants’ feelings and suffering. One participant recounted that “it wasn’t until I actually had a doctor whose wife has migraines where I was treated, like . . . completely different” (P4). Figure 10 is described by the participant-photographer as

that moment of almost relief, that moment that nurse is incredibly compassionate . . . the moment you’ve been waiting for several hours and you’re finally getting the medication that’s going to make you feel better . . . all the pain and suffering is almost going to be over, not completely over, but you’re getting some sort of relief to it. (P4)

Though participants’ relief was often partial, the reduction in pain and suffering was treasured.

Good ED care was also framed through the high skill level of staff and the high-tech equipment on hand. Participants took comfort in the knowledge, diagnostic confidence and quality of explanations provided by care providers. Having their condition investigated and a plan tailored to their needs made participants feel safe. One participant who didn’t know what to expect when she first went to the ED explained she was pleasantly surprised that “nobody is questioning me, and they all believe me” (P2). Being taken seriously and feeling heard and understood was appreciated.

Bad care

Care perceived as “bad” manifested itself in many forms. The ED itself was referred to as a problem, with some participants

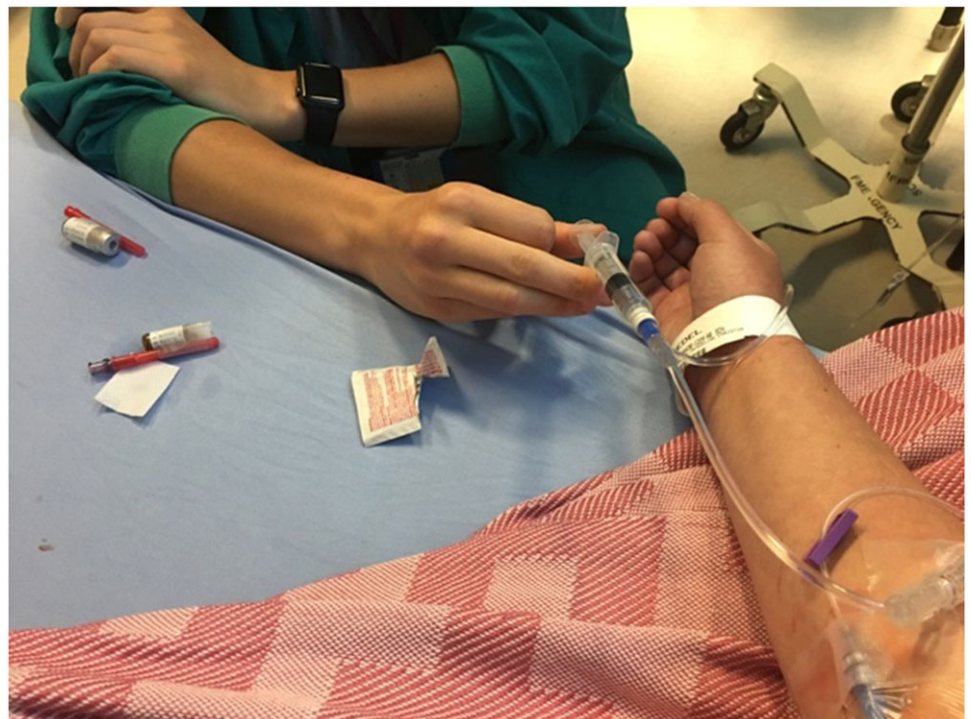


Figure 10. Participant receiving the compassionate administration of medication in the emergency department.



Figure 11. Participant's intravenous bag while receiving dihydroergotamine infusion.

experiencing fearfulness and anxiety being there; one participant explained, “you’re there because you’ve lost control over the headaches, but it’s [also] an uncontrollable place” (P8). Once at the ED, participants experienced frustration with the triage process. In the treatment area, participants were often alone “waiting to find out, like, what’s the next step, like am I going to get more treatment, am I going to get more fluids, am I going to get to go home” (P4). In navigating all the unknowns, “you feel neglected” (P4).

Poor or insufficient communication led to uncertainties, inconsistencies and frustration. Although some participants acknowledged a hampered capacity for discussion while in excruciating pain, they also needed and wanted to be involved in care decisions. Participants wanted their embodied knowledge to be heard; when this knowledge wasn’t heard, participants were frustrated; one said, “I do know what’s best for my head, because it’s on my shoulders” (P8). Another elaborated on the difficulty of asserting their voice, saying “you don’t feel good enough to argue with them” (P1), particularly when it came to medication needs. In Figure 11, the participant-photographer explained that her provider did not explain what medication she was being given. After doing further research on the medication name she read on the bag, she discovered that unpleasant symptoms she experienced were common side effects of it and wished to have had a better conversation about what was being administered as well as alternative options.

Some negative experiences focused on multiple-provider issues, such as difficulties coordinating care and treatments. One

participant noted receiving contradictory advice from providers. She explained that “it just makes you wonder, like one’s saying this, one’s saying that . . . it’s just kinda frustrating” (P2). Protocolized medicine could also interfere with patients receiving the help they were seeking. For example, one participant explained that she was told to remove all of her clothing and put on a gown, which she was reluctant to do (especially since her head was the source of the problem). She was told she needed to because it was the procedure for all patients.

Discussion

This study demonstrated the feasibility of using visual methods with patients in the ED setting and following their acute care experience. These findings highlight the substantial emotional impact that primary headaches can have on patients during exacerbations as well as times without active symptoms. Participants described efforts to maintain hope both in the ED and outside of it, despite threats of hopelessness and living in fear of exacerbations or underlying life-limiting conditions. These findings are echoed in other studies that highlight the impact of recurring and severe headaches on mental health,⁹ the association of increased depressive symptoms with increased headache pain¹¹ and the need for individuals who live with headaches and migraines to maintain hope.⁹ In the acute care setting, participants’ feelings were complex, sometimes even contradictory (e.g., experiencing the ED as both a place of uncertainty and fear, as well as safety, security and relief).

Several important findings are directly applicable to care provision in the ED and offer an opportunity to improve the management of an exacerbation. First, participants desired to be acknowledged as a person, rather than a presentation of symptoms. Second, participants’ exacerbation experiences and ED care were embedded in their lives. Offering legitimacy to their condition and symptoms can ease patients’ suffering and empower them both within the medical context and in their broader lives. Third, participants were grateful for the efforts of providers to make them more comfortable within the ED space (e.g., noise, lights, etc.), even when they were unsuccessful in diminishing their pain. Existing literature suggests that better experiences and patient–physician rapport are associated with following physician advice and improved outcomes.^{20–23} Consequently, the impact of such gestures may be significant. Fourth, partnering with patients in decision-making is important in empowering patients, acknowledging their lived expertise and supporting their identity and agency.²⁴ Ultimately, clinicians have opportunities to improve more than just the physical symptoms of the patient, which should not be underestimated.

In some countries, exacerbations of primary headaches are managed in IV suites and/or specialized headache clinics, in many ways better suited to deal with the needs of these patients.²⁵ In most parts of Canada, however, these alternatives do not exist. Moreover, given the scarcity of primary care providers, the resource limitations in the current healthcare system, alternatives like these, especially those available during off hours, are unlikely solutions for most patients. In the immediate future, we must improve the care provided in the ED for acute headaches. While not a comprehensive evaluation of ED management, this study provides some valuable insight into steps to be taken to improve current practices.

Up front, we acknowledge the small sample size in this study, which facilitated the development of deep insights into exacerbation experiences through rich qualitative data, rather than more broadly generalizable findings. Our aim was to trigger auto-reflection among providers and a realization that such experiences do occur, as well as to point to the importance of making time and space for good care practices in EDs. Using our results may inform patients, providers and administrators on ways to improve care and researchers to propose larger qualitative and quantitative studies.

Limitations

This study was limited by the self-selection nature of the recruitment process. Additionally, the recruitment process was prolonged due to the need to participate in the umbrella study first. Further, the more substantial time commitment and vulnerability required for photovoice participation were likely also deterrents to participation. Altering the recruitment strategy (such as recruitment through specialist offices for participants with previous ED visits) and/or including additional ED sites could diversify the participant population, which may lead to a broader array of experiences being discussed. Second, limited demographic and health history data were collected from each participant. Additional data to characterize the severity and frequency of headaches, formal diagnosis and participants' life situations may have been helpful in interpreting and comparing the data.

Finally, loss to follow-up was substantial in this study. While this is unsurprising given the episodic nature of ED care and the lack of a preexisting relationship with the patient/participant, further consideration of participant engagement is needed to limit the loss to follow-up in similar future studies. It's also important to point out that photovoice studies are complex and rather burdensome for patients with acute conditions to participate in, especially those with residual headaches. We were not surprised by the limited number of patients who followed through after their ED presentation; however, those who did provided a robust series of photographs and interviews that resulted in five key themes.

Conclusion

This study demonstrated the feasibility of using visual methodologies to partner with patients and better understand their lives and ED care experiences during exacerbations of chronic conditions. Engaging in this type of data-generating partnership in the acute care setting is vital to bringing patient's voices to the forefront and to begin identifying gaps in care and caring. Given the overwhelming emotional and personal impact of headaches on the lives of the participants in this study, it is imperative to bring this perspective to ED clinicians to further inform their understanding of patient experiences and personhood. Ultimately, making space and time for humanity in ED interactions will facilitate sharing decisions, acknowledging the patient and ensuring all care is good care.

Acknowledgments. The authors would like to thank the photovoice study participants for sharing their experiences as well as the Emergency Medicine Research Group (EMeRG) at the University of Alberta for their involvement in participant recruitment, screening database management and study material review. The authors also thank B. Sevcik and R. St James for their guidance as knowledge users.

Author contributions. Lynette D. Krebs: Study coordination, study funding, data collection, data cleaning and analysis, manuscript preparation. Nicole Hill: Data collection, data cleaning and analysis, manuscript preparation. Nicholas Lesyk: Study coordination, critical revisions of the manuscript. Cristina Villa-Roel: Study design, study funding, manuscript preparation and critical revisions. Brian H. Rowe: Study design, study co-funding, overall study coordination, critical revisions of the manuscript, corresponding author.

Funding statement. This research was funded by the Alberta Innovates Partnership for Research and Innovation in Health System grant and the EMeRG at the University of Alberta. At the time of this study, Dr Rowe was supported as a Tier I Canada Research Chair in Evidence-based Emergency Medicine from Canadian Institutes of Health Research (CIHR) through the Government of Canada (Ottawa, ON). Dr Rowe's research is now supported by the CIHR through the Scientific Director's Operating Grant (CIHR SOP#: 154602 and 168483). There was no additional external funding received for this study. The funding partners take no responsibility for the conclusions reported.

Competing interests. None.

References

- Barton CW. Evaluation and treatment of headache patients in the emergency department: a survey. *Headache*. 1994;34:91–4.
- Leicht MJ. Non-traumatic headache in the emergency department. *Ann Emerg Med*. 1980;9:404–9.
- Locker T, Mason S, Rigby A. Headache management—are we doing enough? An observational study of patients presenting with headache to the emergency department. *Emerg Med J*. 2004;21:327–32.
- Peters M, Abu-Saad H, Vydelingum V, Dowson A, Murphy M. Migraine and chronic daily headache management: a qualitative study of patients' perceptions. *Scand J Caring Sci*. 2004;18:294–303.
- Leiper DA, Elliott AM, Hannaford PC. Experiences and perceptions of people with headache: a qualitative study. *BMC Fam Pract*. 2006;7:27.
- Ramsey AR. Living with migraine headache: a phenomenological study of women's experiences. *Holist Nurs Pract*. 2012;26:297–307.
- Belam J, Harris G, Kernick D, et al. A qualitative study of migraine involving patient researchers. *Br J Gen*. 2005;55:87–93.
- Risdale L, Noble AJ, Nadeem F, Morgan M. Headache: the patient's view. *J Neurol Neurosurg*. 2014;1:4.
- Rutberg S, Ohrling K. Migraine – more than a headache: women's experiences of living with migraine. *Disabil Rehabil*. 2012;34:329–36.
- Palacios-Cena D, Neira-Martin B, Silva-Hernandez L, et al. Living with chronic migraine: a qualitative study on female patient perspectives from a specialised headache clinic in Spain. *BMJ Open*. 2017;7:17851.
- Heath RL, Saliba M, Mahmassani O, Major SC, Khoury BA. Locus of control moderates the relationship between headache pain and depression. *J Headache Pain*. 2008;9:301–8.
- Oliffe J, Botorff J. Further than the eye can see? Photo elicitation and research with men. *Qual Health Res*. 2007;17:850–8.
- Beveridge R, Clarke B, Janes L, et al. Canadian emergency department triage and acuity scale: implementation guidelines. *CJEM*. 1999;1(3 suppl):S2–S28.
- Sutton-Brown CA. Photovoice: a methodological guide. *Photogr Cult*. 2014;7:169–85.
- Foster-Fishman P, Nowell B, Deacon Z, Nievar AM, McCann P. Using methods that matter: the impact of reflection, dialogue, and voice. *Am J Community Psychol*. 2005;36:275–91.
- Wang C. Photovoice: a participatory action research strategy applied to women's health. *J Women Health*. 1999;8:185–92.
- Bogdan R, Biklen S. *Qualitative Research for Education: An Introduction to Theories and Methods*. Boston: Pearson Education; 2007.
- Rice P, Ezzy D. *Qualitative Research Methods: A Health Focus*. Melbourne: Oxford University Press; 1999.
- Gale N, Heath G, Cameron E, Rashid S, Redwood S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Methodol*. 2013;13:117.

20. Kerse N, Buetow S, Mainous A, Young G, Coster G, Arroll B. Physician-patient relationship medication compliance: a primary care investigation. *Ann Fam Med*. 2004;2:455–61.
21. Decty J, Fotopoulou A. Empathy has a beneficial impact on others in medicine: unifying theories. *Front Behav Neurosci*. 2015;8:457.
22. Rhodes KV, Vieth T, He T, et al. Resuscitating the physician-patient relationship: emergency department communication in an academic medical center. *Ann Emerg Med*. 2004;44:262–7.
23. Hannan J, Sanchez G, Musser E, et al. Role of empathy in the perception of medical errors in patient encounters: a preliminary study. *BMC Res Notes*. 2019;12:327.
24. Weston WW. Informed and shared decision-making: the crux of patient-centred care. *CMAJ*. 2001;165:438–9.
25. Reese O, Wright C, Sandoval A, Lebron B, et al. Establishment of an acute headache infusion clinic as an alternative for emergency department care. *J Neurol Sciences*. 2021;423:117384. DOI: [10.1016/j.jns.2021](https://doi.org/10.1016/j.jns.2021).