KU LEUVEN

FACULTY OF MEDICINE

# Patients' perspectives on tapering of chronic opioid therapy

## A Meta-Synthesis

Master thesis proposed to achieve the degree of master in medicine by

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## Abstract

Background:

Chronic non-cancer opioid usage is a major public health issue leading to significant psychological, physical and economical burdens. Reducing chronic usage is therefore necessary to address this situation. The approach, described in existing guidelines for primary care, concerning the tapering of opioids carry some risks, including: withdrawal symptoms, illicit opioid usage or even suicidality. Furthermore, the perspectives of chronic opioid users during tapering are also not explicitly mentioned in these guidelines. The aim of this meta-synthesis is to provide an overview of patients' perspectives on tapering opioids, and uncover key elements that might hamper primary care clinicians in reducing chronic prescribed opioid use.

Methods:

A meta-synthesis of qualitative studies concerning the tapering of chronic opioid usage was conducted by following the procedure described by Thomas and Harden. Selection of articles was performed after having systematically searched different databases, including Pubmed, Cinahl, Web of Science, Psycarticles and Embase. We included studies that assessed non-cancer chronic opioid use, primary care physicians, deprescription, and qualitative research. Through the process of line-by-line coding analytical themes were generated. The quality of studies was evaluated by using the GRADE-CERQual rating.

Results:

The synthesis included 8 qualitative studies. Four descriptive themes were identified: barriers, facilitators, benefits and risks. For each descriptive theme, the most recurring analytical themes were discussed. Of a total of 16 analytical themes 5 were graded as high, 3 as moderate and 8 as low confidence using the GRADE-CERQual rating. The two key analytical themes were: the patients' fears and the patient-provider relationship.

Conclusion:

Based on the perspectives of patients tapering chronic opioid use, we can recommend, with strong confidence, the following elements to primary care clinicians: taking into account the fears of the patients, maintaining a stable doctor-patient relationship and being mindful of the risk of stigmatization.

## Abstract

Achtergrond:

Niet-kanker gerelateerd chronisch opioïdegebruik vormt een belangrijk maatschappelijk gezondheidsprobleem, met significante psychologische, fysieke en economische lasten tot gevolg. Het reduceren van chronisch gebruik is bijgevolg noodzakelijk. De aanpak, beschreven in de bestaande richtlijnen voor de eerstelijnszorg, voor het afbouwen van opioïden brengt enkele risico's met zich mee, waaronder: ontwenningsverschijnselen, illegaal opioïdengebruik en zelfs suïcidaliteit. Bovendien, worden de perspectieven van chronisch opioïdengebruikers tijdens het afbouwen ook niet expliciet vermeldt in deze richtlijnen. Het doel van deze meta-synthese is om een overzicht te geven van de perspectieven van patiënten op het afbouwen van opioïden, en belangrijke elementen ontdekken die huisartsen belemmeren bij het verminderen van chronisch voorgeschreven opioïdengebruik.

Methodologie:

Een meta-synthese van kwalitatieve onderzoeken naar het afbouwen van chronisch opioïdegebruik werd uitgevoerd, op basis van de procedure beschreven door Thomas en Harden. Vijf databanken werden doorzocht: Pubmed, Cinahl, Web of Science, Psycarticles en Embase. We includeerden studies die voldeden aan de volgende selectiecriteria: niet-kanker gerelateerde chronisch opioïdengebruik; huisartsen; "afbouwen van" en kwalitatief onderzoek. Tijdens het proces van line-by-line coderen werden analytische thema's gegenereerd. De kwaliteit van de studies werd geëvalueerd door het gebruik van de GRADE-CERQual scoring.

Resultaten:

Deze synthese includeerde 8 kwalitatieve studies. Vier beschrijvende thema's werden geïdentificeerd: barrières, facilitatoren, voordelen en risico's. Voor elk beschrijvend thema werden de meest terugkerende analytische thema's besproken. Van de 16 analytische thema's werden er 5 bevonden als sterk, 3 als matig en 8 als laag betrouwbaar volgens het GRADE-CERQual scoresysteem. Twee analytische hoofdthema's waren: angsten van de patiënten en de arts-patiënt relatie.

Conclusie:

Aan de hand van de perspectieven van patiënten bij het afbouwen van chronisch opioïden gebruik kunnen we, met sterk vertrouwen, volgende elementen aan huisartsen aanbevelen: rekening houden met de angsten van de patiënten, onderhouden van een stabiele arts-patiënt relatie en bedachtzaam zijn op het risico van stigmatisering.

## Introduction

Pain is one of the most commonly presenting conditions in primary care, globally (1,2). According to international databases, approximately 15-50% of all pain patients report chronic pain (i.e. pain that persists for three to six months, or more) at some point in their lifetime (3,4). Opioids are frequently prescribed to treat this pain, making them the most commonly prescribed medication of any category in the United States (5). In the United States, the increased prescribing of opioids resulted in the increase of opioid overdose related deaths in the last two decades (3). In 2015, 63.1% of the 52.404 drug overdose deaths involved an opioid, where approximately half involved a prescribed opioid (6–8). Approximately, two million Americans have an opioid use disorder (OUD) resulting in an economic burden of €78,5 billion each year in the United States (8,9). In Belgium, the National Institute for Health and Disability Insurance (INAMI) analysed the prescription of five opioids (tramadol, tilidine, oxycodone, fentanyl and piritramide) outside of the hospital between 2006 and 2016. These five opioids accounted for nearly 80% of the total usage of all reimbursable opioids. During this time period, the number of patients who had consumed at least one prescription of these opioids (outside of the hospital) rose from 638.939 in 2006 to 1.186.943 in 2016. This is nearly 10% of all Belgian citizens (10). In 2014, opioids (mainly heroin, but also fentanyl and derivates) were found in two thirds of all toxicology reports in Belgium concerning drug-induced deaths (11). Many guidelines and education packages suggest health care clinicians to preventing OUD by means of influencing prescribing practices (9,12). However, reducing access to prescribed opioid by restrictions, policies and practices has the potential disadvantage of losing OUD patients who have no therapeutic alternative to opioids. In addition, OUD patients will be driven to the illegal market (9,12). Other risks of the discontinuation of prescribed opioids include withdrawal effects, other substance misuse, mental health crisis, suicidality and loss to follow-up (13,14). The risk of overdose or other severe events is not known (13,14). Therefore, changing policies alone does not seem to be the answer to the problematic use of opioids.

When it comes to discontinuing opioids, there are not many reliable strategies. Generally, tapering is recommended, which includes pharmaceutical support in combination with monitoring of the patient. Often, the patients' commitment is not taken into account (15).

Until now, there seems to be no comprehensive overview of the perspectives of patients when tapering opioids. By obtaining more insight on the psychological difficulties of patients when tapering opioids, we could propose adaptations for the current tapering strategy and help reduce the general misuse of opioids (7,8,15).

Therefore, this review aims to provide an overview of patients' perspectives on tapering opioids, and uncover key elements that might hamper primary care clinicians in reducing chronic prescribed opioid use.

## Methods

### Aim

The aim of this study was the examination of the perspectives of patients with chronic prescribed opioid use in the tapering of opioids and subsequently laying the foundation for the further development of recommendations for primary care clinicians.

### Study design

We conducted a qualitative meta-synthesis. We decided to perform a thematic synthesis as it is our aim to generate prominent themes and key messages about the facilitators and barriers regarding the tapering of opioids. Thematic synthesis uses a pre-planned approach with search strategies seeking all available studies about the subject. We based the construction of our synthesis on already published meta-synthesis protocol (16,17). To further enhance our transparency in reporting the synthesis of qualitative research, we used the ENTREQ© checklist (18).

### Identification and selection of studies

The following electronic databases were searched in July 2020: Pubmed, Cinahl, Web of Science, Embase and Psycarticles.

We developed our search using three keywords, namely “opioids”, “deprescription” and “primary care”. For each theme and for each database, we found Mesh-terms and Title/Abstract text words. Subsequently, we developed a search strategy for each database by combining the latter (Appendix A).

Following the ENTREQ guidelines, we searched grey literature for additional articles in following databases: greylit, opengrey, Scopus, Mednar and NIHlibrary.

Inclusion criteria were male and female; 18+; English language; non-cancer chronic opioid use primary care physicians; deprescription and study designs solely based on qualitative methodology, including focus groups, or interviews, among others.

Exclusion criteria were studies involving opioids in the context of cancer care, palliative care, non-primary care and non-medical use; non-prescription opioids (e.g., heroin); opioid substitution therapy; studies using quantitative or mixed methodologies.

Inclusion and exclusion were based on a consensus of all reviewers.

We entered our search query in each of the separate electronic databases. The resulting studies were then gathered and entered in an online bibliographic software program (Rayyan©). This program detected the duplicates automatically which we then deleted.

Thereafter, two pairs of independent reviewers screened all titles and abstracts and selected the studies according to our inclusion criteria. Conflicts were resolved by consensus. In those cases where no consensus could be reached, a decision was made based on a simple majority vote. The full texts of the potentially relevant articles were then examined, again by two pairs of independent reviewers, and a last selection was done.

**Quality Assessment of the Included Studies**

To critically assess the quality of the included articles the Critical Appraisal Skills Programme (CASP©) qualitative research checklist was used. The CASP checklist consist of 10 questions related to relevance, appropriateness, research design, recruitment, data collection, reflexivity, ethical issues, data analysis, findings and value of the research (19). Appraisal was conducted by 2 independent authors (L.E., M.E.), and conflicts were resolved by consensus. If no consensus was reached, a third reviewer (L.W.) was consulted and a decision was made based on a simple majority vote.

**Data abstraction and synthesis**

We then extracted the following characteristics of the selected studies: research question or summary of the study's aim, country where the study took place, number and mean age of participants, data collection method and analysis method.

In order to abstract data, only sections on patients' views were included, usually in the form of quotations from chronic opioid patients themselves. Afterwards, the results were electronically extracted and entered into the Nvivo© program software for qualitative data analysis.

Four reviewers (L.E., M.E., L.W., C.L.) were involved in the thematic analysis of the selected literature.

The extracted data was processed with the method of 'line by line coding'. Comparisons within and between studies were made by organising the codes into broader descriptive themes. An inductive approach was used when deriving the themes. By consensus, we selected the most applicable quote for the described themes because of the extensive number of quotes in the articles.

The researchers formed two separate groups to perform the data analysis. The first group (L.E. and M.E.) analysed fifty percent of the data independently and the second group (L.W. and C.L) analysed the other fifty percent independently without consultation. Coding progress was discussed regularly in team to coordinate the process. After the translational work, the researchers matched themes across papers to develop descriptive themes while ensuring that each concept captured similar codes from different articles. A table with the Summary of Findings was created and a rate of confidence was given using the GRADE-CERQual tool for each descriptive theme (20). By appraising the methodological limitations (using the CASP

questionnaire), the relevance (applicability from the included studies to the context), the coherence (the fit between data from the primary studies and the review findings) and the adequacy (degree of richness and the quantity of data) an overall CERQual rating could be given to each review finding. These ratings are catalogued as high, moderate, low or very low. This process was done as a group.

During the last step, we mapped the analytical themes to create a framework for the tapering of opioids. This form of interpretation goes beyond the descriptive themes to enable a higher level of comprehension resulting in new insight on this subject. To underline our results, we used quotes found in the selected articles (Appendix B). Based on this framework, implications for intervention development were formulated. This process was first done independently and then based on a consensus of all reviewers.

## Results

A total of 11 968 articles were screened and 6242 duplicates were removed, after which we selected eight articles based on our selection criteria. Five articles described the patient's perspectives on the tapering of chronic opioid in primary care (21–25), one article described unsupervised tapering (26), one article described presumed tapering (27) and one article was situated partially in specialty care and partially in primary care (28). We were not able to generate any relevant articles in the Psycarticles database and grey literature databases with the adapted Mesh-terms and Title/Abstract text words. The process of our selection of articles can be found in the PRISMA flow chart (see figure 1). The characteristics of each study were summarized in a table which can be found in the Appendix (Appendix C). The quality assessment of the found studies based on the CASP criteria can be found in the appendix (Appendix D).

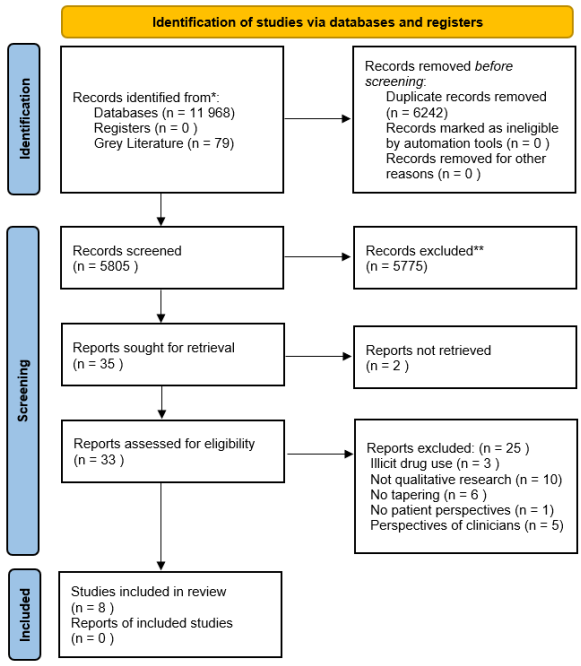



*Figure 1: Prisma flow chart*

Based on consensus, we found 6 studies to be of high quality (22–26,28) and 2 studies to be of moderate quality (21,27). The rate of confidence of our findings based on CERQual criteria can be found in the appendix (Appendix E), 5 were of high confidence, 3 of moderate

confidence and 8 of low confidence. Subsequently, we mentioned the rate of confidence in the title of each section.

Through analysis of our selected articles, we identified four main categories that describe patients' views on tapering, namely barriers, facilitators, benefits and risks. For each category, we chose to discuss the most frequently recurring themes.

**1. Perceived barriers**

Barriers include the reasons why patients are unwilling or reluctant to taper opioids.

1.1 Patients' fears (High confidence)

The prospect of tapering opioids might evoke fear of symptoms that are associated when someone discontinues the use of opioids. These include sickness or flu-like symptoms, headaches, gastro-intestinal problems and general malaise (22).

> *"I don't think they're aware of how bad withdrawals are. I mean there's vomiting bile. There's stomach cramps, there's the cold shakes and fever. I mean it's pretty bad."* (22)

Chronic pain patients also fear that, due to a decrease in the daily dose of opioids, they will experience more pain or even an uncontrollable amount of it. Some patients even felt threatened by this fact. (21,27,28)

> *"…patients felt threatened by the discontinuation and deprived of their medication and resented enduring trials to optimize alternate medication regimes."*(28)

Another important fear we found is one where patients are afraid of the lack of alternative (pain) medications. One study (28) described that chronic pain patients felt the need to make additional pain medications available, because they had already exhausted alternatives. In another study (27) we found that patients may assume that no other substitute would be given to treat the pain, when opioid medications are decreased.

1.2 Discordances in the patient provider relationship (High confidence)

*1.2.1 Misinformation about tapering*

One study (21) described that chronic pain patients had various ideas about what tapering really means. For example, interchangeable usage of the terms 'taper' and 'detox' tended to associate tapering with withdrawal symptoms, which we already discussed as a barrier to tapering.

> *"Patients who used the terms "taper" and "detox" interchangeably tended to associate tapering with withdrawal symptoms."* (21)

In addition to another study (21,24) we found that patients and providers disagreed or were not entirely honest on their reasons why to taper opioids. In turn, this leads to discussions between chronic pain patients and clinicians, which could be contentious and frustrating.

> *"…conveying understanding and negotiating about tapering were not always successful, and the result was conversations that could be contentious and frustrating."* (24)

In Chang et al. (28) we found that in one case, the primary care physician did not provide the correct or the adequate amount of information concerning opioids, when they first prescribe them. This led to a lack of trust in the medication related-information provided by the physician for the discontinuation of opioids. We also found that, conflicting opinions among physicians were very confusing for patients, which in turn led to misinformation about opioids (28).

*1.2.2 Communication and guidance problems*

Chronic pain patients sometimes feel or have the experience that they are not taken seriously by their general practitioner. The physician doesn't show enough care, isn't listening or just simply doesn't want to listen to the patient during the tapering process. In turn, this makes the patient feel misunderstood, or gives the patient the feeling that he's just making something up to get his medicine. (24,25)

> *"They didn't really allow me to speak about anything or tell them anything: they just came in and looked at me really quick. (…) The thing is that the doctor just doesn't (…) want to listen to me about my pain. They just… it's like they thought that I was making it up or something just try to get the medicine. They made me feel like (…) I was an addict trying to get fixed."* (25)

Another communication problem we found in Chang et al. (2017), is the difficulty in consulting the general practitioner. This problem can sometimes be at the root of being poorly informed, for example as to why opioids are being discontinued (28)

Patients felt like they were not being involved in the decision-making concerning the tapering of opioids. They felt like the decisions were made over their head by their physicians, and that they didn't have anything to say in the matter. This led to feelings of being left out or being neglected. (24,25)

Chronic pain patients can have feelings of being lost or betrayed by their primary care physician when they unilaterally tapered or stopped prescribing opioids. This can lead to a break in trust between the doctor and the patient which hampers tapering of opioids (21).

Several patients reported that their physicians were more focused on tapering opioids rather than treating pain. This illustrates that doctors may not pay enough attention to the specific needs of the patient and isn't providing any guidance when the patient encounters difficulties during the tapering of opioids (21).

> *"Several patients reported experiences with clinicians who they perceived as focused on tapering opioids rather than treating pain: When you say you want to go down and get off of it, I'm making an initiative. He's not asking me to, and yet when I say, "Well, maybe I shouldn't have gone all the way off. At least maybe I should have something as a backup for when it's really, really bad." He comes back to me and says, "Uh, no, no. Sorry, we don't go backwards.""*(21)

Another reason for the break in trust between patient and provider comes from patients feeling that their general practitioner shows favouritism towards other patients, when it comes to prescribing pain medications (25).

1.3 The impact of government regulations on taking and reducing opioids (Low confidence)

Some patients mention that policy changes force them to visit their physician more often, which causes practical difficulties. These policy changes may include reducing refill doses to 6 weeks instead of 12 or requiring classes of physiotherapy to get a prescription of opioids. It places an additional burden on their daily lives, which was already affected by the chronic pain (25).

> *"I get drug tested about (every) 2 or 3 months. (…) I think it (the rules) made it more difficult for patients to get their medicines (…) it's hard to take off work to be able to go in every month or 2 months to the physician, whereas it used to be able to get refills every 3 to 4 months without having to go to the physician. (Now) it's usually every 6 weeks I see (the pain management) doctor."* (25)

Also some patients perceived the government's policies regarding opioid use as unfair, and that they feel being treated as addicts while they perceive themselves as not abusing opioids (28).

1.4 The negative social influences and emotions around tapering (High confidence)

Returning themes emerging from interviews with opioid users were a feeling of judgement and a lack of support by their surrounding and professionals (21); fear of stigmatization and judgement hampering seeking of help (23,24,26); and circumstances (21) (social and health issues) interrupting attempts of tapering.

Some patients felt judged by their treating physician (24), or they felt being compared with illicit drug users (26–28). Some feared stigmatization causing them to hide their opioid use from family, friends, and even their doctors (e.g. codeine sold over the counter). (25–27)

> *"[My doctor] treated me like I was a druggie or something, and I don't take anything that's not prescribed or more than is prescribed. I've been on [the opioids] for years and years, and what [another doctor] prescribed me, I wasn't even taking all of it. [Now the dose] is cut to less than half of what I used to take."* (24)

Other patients indicate that their current family- or work situation doesn't allow tapering, and they postpone it until their situation changes (21). Another reason for failure to taper was a change in health status, for example (repeated) injuries leading to increased pain killer usage (21).

1.5 . Problematic attitudes towards tapering (Moderate confidence)

Some patients are harder to motivate to taper their opioids, because of the perceived beneficial effects of opioids (27). They think the risks of opioid (mis)use don't potentially apply to them, or value pain control more than safety (22). They think they're doing well because they are following the instructions from their provider (24). Furthermore, some don't believe they're able to live without opioids, they see chronic opioid therapy as the only answer to their pain, not finding sufficient relief through alternatives (22,25). Some perceive tapering opioids as cruel and some experienced cost barriers for alternatives (27,28).

> *"I've been on opiates, you know, for most of my adult life now, and I'm probably going to be on them for the rest of my life. I mean you're not going to cure what's wrong with me . . . so I'm always going to need something."* (22)

**2. Perceived benefits of opioid tapering**

The following will include benefits of opioid tapering.

2.1. Reducing pain medication does not equal increasing pain (moderate confidence)

Several patients stressed that their pain level wasn't worse after opioid tapering and in some cases their pain even improved (22,23,28).

2.2. Improvement of quality of life in multiple dimensions

*2.2.1. Resolution of negative side effects of chronic opioid usage (moderate confidence)*

Many patients who have tapered or discontinued opioid usage find that even though the tapering process was difficult, the advantages of tapering outweigh the disadvantages. An improvement of quality of life can be partially explained by the disappearance of side effects

of opioid therapy. Patients mention having more energy and having a clearer mind, consequently filling their days with meaningful activities (22,23).

> *"My mind is much clearer because I'm not taking this stuff that…the pain killer that works on your mind. So I am doing so much better."* (22)

*2.2.2. Improvement of social interactions (high confidence)*

By tapering or discontinuing opioid usage with the consequent reduction of side effects, patients found an improvement in their social interactions (22).

> *"My family is really pleased too. Like, I'm more alert now. They say I'm engaged more again and talking to them. I don't just sit there and zone out."* (22)

**3. Perceived facilitators**

The following will include facilitating reasons for patients to successfully taper.

3.1. Awareness of problematic opioid usage and requesting help (Low confidence)

In many cases the tapering process starts when chronic opioid users realize their opioid usage is problematic. In some cases the awareness came from the patients themselves, in other cases this was triggered by their provider or their surroundings. Often, this realization of problematic opioid usage was followed by a request for help when recognizing their needs for a reduction or a complete cessation of opioid usage. As some chronic pain patients do not have any idea at all of how to taper, they would like to be informed as to how to tackle this and if there are any alternative pain management options available (21,26,28).

> *"I'm struggling to say this, but I've got a painkiller addiction involving codeine. I really would like to get help but I'm unsure of how to do this. It's been going on for over three years now and is getting worse (…) I am aware I am causing myself harm and know I should stop, but how? Ideas of how to stop would be really appreciated."* (21)

3.2. Individual incentives to taper (high confidence)

Many patients expressed their concerns of being addicted and being physically and psychologically dependent on opioids for life as an incentive to taper (27).

Another incentive was having identity struggles, being worried about the perceptions of others and not wanting to be a "pain patient". Reclaiming their identity from their life before opioid usage and reclaiming their place in their social surroundings by not letting their addiction run their lives was also mentioned (21).

> *"I want to reclaim certain things in my life that were enjoyable, and I feel pain medication has altered."* (21)

Some patients started tapering because they wanted to take less medication or wanted to have a better health. Having negative side effects of opioids was a very common incentive throughout the examined studies. While their pain was diminished, this was counteracted by having adverse side effects varying in type and intensity. Among others the following were included: Lack of concentration, lethargy, withdrawal symptoms, dependence, toleration and just not liking the feeling of being on opioids. This not only affected their personal quality of life but also their social and work surroundings (21,25–27).

3.3 Realization of the tapering process and taking responsibility (low confidence)

By understanding that tapering needs planning and sustained effort and understanding there will be a lot of changes, successfully stopping opioid use becomes more likely (21,28).

> *"It's a process, it's not something that you do one day and it's gone the next."* (21)

3.4 Importance of good patient provider relationship as a means to successfully taper.

A common theme throughout the found perceptions of patients during the tapering process is the importance of adequate communication between patient and provider.

*3.4.1 Open communication (moderate confidence)*

Several patients mentioned, among other things, the importance of mutual honesty as a requirement for successful opioid tapering. Other praised attributes were being supportive, non-judgmental, flexible, and accessible. Patients who had a positive relationship with their provider tended to trust their provider more throughout the tapering process. This positive and open communication sometimes led to more understanding and acceptance of the need to taper (21,22,24,25).

> *"The best thing about it was that nobody acted like I was a bad person because I was on these medications and was having to be going through this really slow process of coming down off of them."* (22)

*3.4.2 Having a safety net (moderate confidence)*

Finally, providing a safety net lets patients feel supported by their care provider. The willingness from providers to adjust the tapering plans in case of changes in patients' lives proves to be a facilitator in initiating and sustaining opioid tapering (21,24).

> *"I knew she wasn't just going to take me completely off of [the opioids] because I would be miserable... She just said, 'We'll try this, but if you need to go back to where you were, I'll do that."* (24)

James et al. found that, when searching for participants in an opioid tapering research, the ability to withdraw from the study and return to usual care at any time was very important and proved to be a facilitating factor in initiating opioid tapering (27).

3.5 Positive social and emotional influences (low confidence)

Patients described social support as a crucial facilitator during the tapering process. Some patients noted that the involvement of their family was crucial in the identification of poor self-care or helped in the day-to-day decision-marking during the process (21,22).

Several patients noted that shared experiences of peers helped them to keep motivated during their tapering by sharing their improved quality of life (22).

> *"You have to get people to people. On paper, [patients] don't care. They really don't. They have to have some one-on-one quality time with a real person who talks about real issues .. . It's almost like me or you watching TV. You don't know if that's a real person doing that or acting. You know, it's gotta be real. The doctors have got to really want to do this with these people, and you have to really find other patients that are willing to talk."* (22)

**4. Perceived tapering risks / risks paired with tapering**

In the following, we describe the risks associated with the opioid tapering.

4.1 Stressful patient provider relationship (low confidence)

4. 1. 1. Fear of losing normal care

Losing the normal care of physicians is an important risk factor during the tapering process. Patients described the small error margin of opioid patients in their relationship with their clinicians especially during their tapering process. Patients understand the central role of primary care clinicians in their opioid regimen. Patients were therefore often reluctant to challenge their clinicians' decisions when negotiating opioid dosing or the rate of tapering. Patients feared for potential alterations in their relationship, alterations in their normal daily care or feared for being labeled as an addict (21).

> *Henry et al. "Patients were often reluctant to challenge clinicians for fear of losing access to other medical services or of being labeled a "drug seeker."* (21)

4. 1. 2. Switching clinicians

Some patients even see switching clinicians as their only option for resolving their persistent legitimate or invalidate disagreements (21).

> *"I decided that I needed to start tapering. And…brought it up with my doctor that I currently have. The one I have right before her. I ended it, because she told me that I*

*would never be off of them, and she doesn't ever see me going off, and I just couldn't accept that. …So, I went and changed doctors."* (21)

4. 2. Seeking "illicit" alternatives (low confidence)

A few patients considered seeking alternatives in the illicit market, one patient overdosed as a consequence of accepting counterfeit opioid alternatives. Another patient imagined buying heroin or even injuring himself in order to obtain legit opioids (21,24).

*"I was just going to tell you to be honest with you. If I can't get my own script, then they are going to make me go out and ask for people, do you have any pain medicine? You know? I don't want to go that far."* (24)

4.3 Unsupervised self medication (low confidence)

Most patients admitted maintaining an opioid "stash" for unexpected shortages or sudden flares of pain. Undoubtedly this "stash" is an absolute risk factor for potential deterioration during the tapering process. Some patients stated that having this emergency supply gives a psychological benefit for reducing fears of new pains or opioid deficits (21).

4.4 Opioid prescription restrictions as a trigger for emotional distress in patients (low confidence)

4. 4. 1. Fear of limited accessibility to opioids

Patients worry that changes of opioid prescription guidelines might limit their access to opioids. Sometimes this distress can be severe enough to prompt patients seeking counselling from a mental health professional or even another primary care physician (23,25).

4. 4. 2. Negative influence on patient-provider relationship

Consequently, these opioid prescription restrictions also negatively influence the doctor-patient relationship. Patients perceive that more strict laws concerning opioids result in the feeling of being more controlled by their physician (25).

4. 4. 3. Reducing intake without thinking about the increase in complications

These government-controlled restrictions on opioid prescribing obviously have the effect of reducing the intake of opioids. For some patients, this is done without taking into account the increased pain and the complications that follows (25).

Patients think the policy changes made them less of an individual, but more abstracted into a public health problem. These policy changes concerning opioids are made because of the increasing public health problem of addiction and overdosing. This has implications for the people who need the medication for chronic pain and maintain a good quality of life (25).

*"I was doing just fine (before the law change). Now I have to struggle, suffer, to make to the next time that I can get my medicine. And I don't think it's fair to me because if I can take my medicine a little more regularly, I would be able to do more and thought that we have a better effect in your life and I don't think that law, people, politicians, or anybody should be able to tell anybody that's in pain what type of medicine that they can take."* (25)

## Discussion

This meta-synthesis of 8 qualitative studies on the perspectives of patients during the taper of chronic opioid use enabled us to identify four superordinate themes which describe barriers, benefits, facilitators and risks. Two transversal themes in our meta-synthesis were the patients' fears and patient-provider interaction. The fears of patients span over physical, emotional, social and economic domains, negatively influencing the tapering process. Furthermore, stable patient-provider interaction is crucial to the tapering process, as it is present in all subordinate themes except in benefits. Negative perceptions include the fears of withdrawal symptoms, fears of stigma, fears of losing their normal care, fear of loss-of-function, fears of lack of alternative medication, and experiencing the patient-provider relationship to be stressful. Positive perceptions include improvement of social interactions, resolution of negative-side effect and less medication.

A remarkable finding of our research is the contradiction between the fears and thoughts that play when tapering opioids. On the one hand, the patients fear they will experience severe withdrawal symptoms and on the other hand they don't see themselves as being addicted to opioids. This contradiction evokes a lot of resistance as they feel stigmatized. Therefore, open and emphatic communication is key to bilaterally understand the reasons for tapering and consequently minimalize stigma. This stigma can further be enhanced by government guidelines restricting general practitioners to prescribe opioids. These restrictions don't take into account the patient as an individual but more as a public health problem, which inevitably leads to stigma. These findings are similar to the contradiction we found in another empirical study concerning the addiction to drugs and alcohol (29,30). More recent research concluded that opioid tapering can exacerbate stigma among patients with chronic pain, more so if the patient perceives that their pain is not being validated (31).

Another finding of our research is the importance of the patient-provider relationship. The quality of the relationship will influence the tapering process: a good relationship facilitates

tapering opioids, a bad relationship will be a barrier or could potentially be a risk. Empirical research from the providers' perspective highlights the importance of a good patient provider relationship and the positive effect on the tapering process (32). According to Dowell et al. patient involvement during the tapering process is an important feature for success and underlines the importance of a good patient provider relationship (33).

A strength of our study was that it was the first meta-synthesis about patients' perspectives of tapering chronic opioid use. This meta-synthesis was based on the perspectives of at least 350 patients. Another strength was that protocols were followed for both reporting (ENTREQ) and quality appraisal (CASP and GRADE-CERQual).
A very extensive search was done, including several grey literature databases. Moreover, the research team has been in constant deliberation throughout the review process. Overall we found 6 studies to be of high quality (22–26,28) and 2 studies to be of moderate quality (21,27). Furthermore, the use of GRADE-CERQual allowed us to find how much confidence to place in our findings. We graded 5 analytical themes to be of high confidence, 3 of moderate confidence and 8 of low confidence. We reduced the subjectivity of our analytical themes by initially working independently, subsequently comparing the findings and repeatedly reflecting in group to achieve consensus.
The weakness of our meta-synthesis was that we only found eight qualitative articles of which 3 were questionable on relevance. This questionability was derived from the small numbers of participants and the overlay between primary care and secondary care. Furthermore, the meta-synthesis included six American studies, one Canadian study and one from the UK, thereby limiting the relevance and implications for the European context. The span of our research was 3 years, but after our initial research and selection in 2020, we didn't perform a new search in the second year and potentially missed new relevant articles. In general, more than half of the analytical themes were of moderate or low confidence.

Our results suggest to reconsider the patient-provider relationship in context of the taper of chronic opioid use. The objective is to adequately inform patients, individualize the tapering process with shared decision making, providing a safety-net, reassuring accessibility and continuity in care, reassuring mutual honesty and a non-judgmental approach. These objectives will prevent unnecessary fears during tapering, misconceptions with tapering and distrusts between patient and provider. In the tapering process there needs to be more emphasis on positive perceptions. Existing (Dutch) guidelines on the tapering of opioids are mostly based on consensus and not on evidence (34). Therefore, our findings can provide the foundations for more in-depth research, necessary to improve existing guidelines for the tapering of non-cancer chronic opioid users.

## Conclusion

The aim of this meta-synthesis is to examine the perspectives of patients on the tapering of chronic opioid usage. In doing so, we ought to give primary care physicians some recommendations to assist them in guiding patients in the tapering of non-cancer chronic opioid usage. This study gives a summary of the barriers, benefits, facilitators and risks associated with the tapering of non-cancer chronic opioid usage. Key elements, retrieved from high confidence analytical themes, are maintaining a stable patient provider relationship, taking the fears of patients into account, and be prudent with the risk of stigmatisation during the tapering. More in-depth research is necessary to improve existing guidelines for the tapering of non-cancer chronic opioid users.

## Conflict of interest

The authors have no conflicts of interest to disclose.

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## References


1. Finley CR, Chan DS, Garrison S, Korownyk C, Ccfp MD, Kolber MR, et al. What are the most common conditions in primary care? [Internet]. Vol. 64, Canadian Family Physician | Le Médecin de famille canadien }. Available from: www.cfp.ca.
2. Daubresse M, Chang HY, Yu Y, Viswanathan S, Shah ND, Stafford RS, et al. Ambulatory diagnosis and treatment of nonmalignant pain in the united states, 2000-2010. Medical Care. 2013;51(10):870–8.
3. Barth KS, Maria MM, Lawson K, Shaftman S, Brady KT, Back SE. Pain and motives for use among non-treatment seeking individuals with prescription opioid dependence. Am J Addict. 22(5):486–91.
4. Austin RC, Fusco CW, Fagan EB, Drake E, Pacious J, Dickens H, et al. Teaching opioid tapering through guided instruction. Family Medicine. 2019;51(5):434–7.
5. Kuehn BM. Opioid Prescriptions Soar Increase in Legitimate Use as Well as Abuse [Internet]. Available from: https://jamanetwork.com/
6. Schuchat, A., Houry, D., & Guy, G. P. J. New Data on Opioid Use and Prescribing in the United States. Physiol Behav. 2017;176(1):139–48.
7. Rudd RA, Seth P, David F, Scholl L. Morbidity and Mortality Weekly Report Increases in Drug and Opioid-Involved Overdose Deaths — United States. 2010;65:2010–5.
8. Guy Jr GP, Zhang K, Bohm MK, Losby J, Lewis B, Young R, et al. Morbidity and Mortality Weekly Report Vital Signs: Changes in Opioid Prescribing in the United States, 2006–2015. Morbidity and Mortality Weekly Report [Internet]. 2015;66(26):697–704. Available from: https://www.cdc.gov/mmwr/volumes/66/wr/pdfs/mm6626a4.pdf%0Ahttps://www.cdc.
9. Richard J. Bonnie, Morgan A. Ford, Jonathan K. Phillips. Pain Management and the Opioid Epidemic. Pain Management and the Opioid Epidemic. 2017.
10. EMCDDA. The drug problem in Belgium at a Glance. 2019.
11. FAMHP. Abuse of opioid analgesics – for rational use of opioids. 2020;
12. OECD. Addressing Problematic Opioid Use in OECD Countries. OECD Health Policy Studies [Internet]. 2019. Available from: https://doi.org/10.1787/a18286f0-en.
13. Berna C, Kulich RJ, Rathmell JP. Tapering long-term opioid therapy in chronic noncancer pain: Evidence and recommendations for everyday practice. Mayo Clinic Proceedings [Internet]. 2015;90(6):828–42. Available from: http://dx.doi.org/10.1016/j.mayocp.2015.04.003
14. Demidenko MI, Dobscha SK, Morasco BJ, Meath THA, Ilgen MA, Lovejoy TI. Suicidal ideation and suicidal self-directed violence following clinician-initiated prescription opioid discontinuation among long-term opioid users. General Hospital Psychiatry

[Internet]. 2017;47(March):29–35. Available from: http://dx.doi.org/10.1016/j.genhosppsych.2017.04.011

15. Deborah Dowell, Wilson M. Compton BPG et al. Patient-Centered Reduction or Discontinuation of Long-term Opioid Analgesics: The HHS Guide for Clinicians. Physiol Behav. 2017;176(5):139–48.
16. Lachal J, Revah-Levy A, Orri M, Moro MR. Metasynthesis: An original method to synthesize qualitative literature in psychiatry. Frontiers in Psychiatry. 2017 Dec 1;8(DEC).
17. Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. BMC Medical Research Methodology. 2008;8.
18. Tong A, Flemming K, McInnes E, Oliver S, Craig J. Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. BMC Medical Research Methodology. 2012;12.
19. Critical Appraisal Skills Programme (2019). CASP (Qualitative Studies) Checklist. [online] Available at: 06/20: Date 06/20.
20. Lewin S, Bohren M, Rashidian A, Munthe-Kaas H, Glenton C, Colvin CJ, et al. Applying GRADE-CERQual to qualitative evidence synthesis findings-paper 2: How to make an overall CERQual assessment of confidence and create a Summary of Qualitative Findings table. Implementation Science. 2018 Jan 25;13.
21. Henry SG, Paterniti DA, Feng B, Iosif AM, Kravitz RL, Weinberg G, et al. Patients' Experience With Opioid Tapering: A Conceptual Model With Recommendations for Clinicians. Journal of Pain. 2019 Feb 1;20(2):181–91.
22. Frank JW, Levy C, Matlock DD, Calcaterra SL, Mueller SR, Koester S, et al. Patients' perspectives on tapering of chronic opioid therapy: A qualitative study. Pain Medicine (United States). 2016;17(10):1838–47.
23. Gruß I, Firemark A, Mayhew M, McMullen CK, DeBar LL. Taking opioids in times of crisis: Institutional oversight, chronic pain and suffering in an integrated healthcare delivery system in the U.S. International Journal of Drug Policy. 2019 Dec 1;74:62–8.
24. Matthias MS, Johnson NL, Shields CG, Bair MJ, MacKie P, Huffman M, et al. "I'm Not Gonna Pull the Rug out From Under You": Patient-Provider Communication About Opioid Tapering. Journal of Pain. 2017 Nov 1;18(11):1365–73.
25. Achkar M al, Revere D, Dennis B, Mackie P, Gupta S, Grannis S. Exploring perceptions and experiences of patients who have chronic pain as state prescription opioid policies change: A qualitative study in Indiana. BMJ Open. 2017 Nov 1;7(11).
26. Lee E, Cooper RJ. Codeine addiction and internet forum use and support: Qualitative netnographic study. JMIR Mental Health. 2019 Apr 1;6(4).

27. James J, Lai B, Witt T. Patient Engagement Survey Regarding Future Double-Blinded, Randomized Controlled Trial of Tapering of Chronic Opioid Therapy. Journal of Primary Care and Community Health. 2019;10.
28. Chang F, Ibrahim S, Twycross A. Perceptions of community-dwelling patients and their physicians on OxyContin® discontinuation and the impact on chronic pain management. Pain Research and Management. 2017;2017.
29. Cheetham A PLBALDNS. The Impact of Stigma on People with Opioid Use Disorder, Opioid Treatment, and Policy. Subst Abuse Rehabil. 2022;13:1–12.
30. Taha S, Maloney-Hall B, Buxton J. Lessons learned from the opioid crisis across the pillars of the Canadian drugs and substances strategy. Vol. 14, Substance Abuse: Treatment, Prevention, and Policy. BioMed Central Ltd.; 2019.
31. Benintendi A, Kosakowski S, Lagisetty P, Larochelle M, Bohnert ASB, Bazzi AR. "I felt like I had a scarlet letter": Recurring experiences of structural stigma surrounding opioid tapers among patients with chronic, non-cancer pain. Drug and Alcohol Dependence. 2021 May 1;222.
32. Kennedy LC, Binswanger IA, Mueller SR, Levy C, Matlock DD, Susan L, et al. " Those Conversations in My Experience Don ' t Go Well ": A Qualitative Study of Primary Care Provider Experiences Tapering Long-term Opioid Medications. 2018;2201–11.
33. Dowell D, Haegerich TM. Changing the conversation about opioid tapering. Vol. 167, Annals of Internal Medicine. American College of Physicians; 2017. p. 208–9.
34. Kadir-Klevering F DZ, Keizer D. NHG-Standaard Pijn (M106).

## Appendix

APPENDIX A

| Research strategy Pubmed | | |
|---|---|---|
| Search | Query | Results |
| #1 | "Narcotics"[Mesh] OR "Morphine"[Mesh] OR "Morphine Derivatives"[Mesh:NoExp] OR "Morphinans "[Mesh:NoExp] OR "Buprenorphine"[Mesh] OR "Codeine"[Mesh] OR "Oxycodone"[Mesh] OR "Hydromorphone"[Mesh] OR "Pentazocine"[Mesh] OR analgesic*[Tiab] OR opioid*[tiab] OR opiate*[tiab]OR narcotic*[tiab]OR morphin*[tiab] OR buprenorphin*[tiab]OR MS contin[tiab]OR MScontin[tiab]OR codeine[tiab]OR oxycodone[tiab] OR "Hydromorphone"[Mesh] OR hydromorphon*[tiab]OR "Pentazocine "[Mesh] OR pentazocine[tiab] | 232,571 |
| #2 | "Primary Health Care "[Mesh:NoExp] OR "Physicians, Primary Care"[Mesh] OR "Physicians"[Mesh:NoExp] OR "Physicians, Family"[Mesh] OR "General Practitioners"[Mesh] OR “primary health care” [tiab] OR “primary healthcare” [tiab] OR “primary care” [tiab] OR physician*[tiab] OR “general practitioner*”[tiab] OR GP[tiab] OR GPs[tiab]OR “general practice” [tiab] OR “family doctor*”[tiab] OR “family practitioner*”[tiab] | 664,140 |
| # 1 AND #2: #3 | | 9,980 |
| #4 | "Deprescriptions"[Mesh] OR deprescri*[tiab] OR discontinu*[tiab] OR stop*[tiab] OR reconciliat*[tiab] OR reduce[tiab] OR reduction[tiab] OR decreas*[tiab] OR diminution[tiab] OR cut[tiab] | 4,064,681 |
| #3 AND #4: #5 | | 2,491 |
| Research strategy Embase | | |
| #1 | 'opiate'/exp OR 'opiate*':ti,ab,kw OR 'opioid*':ti,ab,kw OR 'opiate agonist'/exp OR 'codeine'/exp OR 'codeine':ti,ab,kw OR 'narcotic analgesic agent'/exp OR 'fentanyl derivative'/exp OR ‘fentanyl’:ti,ab,kw OR 'tramadol'/exp OR 'tramadol':ti,ab,kw OR 'oxycodone'/exp OR 'oxycodone':ti,ab,kw OR 'dihydromorphine'/exp OR 'dihydromorph*':ti,ab,kw OR 'morphine derivative'/exp OR 'buprenorphine'/exp OR 'buprenorphine':ti,ab,kw OR 'hydrocodone'/exp OR 'hydrocodone':ti,ab,kw OR 'morphine'/exp OR 'morphin*':ti,ab,kw OR | 581,244 |

| | | |
|---|---|---|
| | 'metazocine'/exp OR 'metazocine':ti,ab,kw OR 'pentazocine'/exp OR 'pentazocine':ti,ab,kw OR ‘narcotic*’:ti,ab,kw OR ‘analgesic*’:ti,ab,kw | |
| #2 | 'primary medical care':ti,ab,kw OR 'primary health care'/exp OR 'primary health care':ti,ab,kw OR ‘primary healthcare’:ti,ab,kw OR ‘primary care’:ti,ab,kw OR ‘first line care’:ti,ab,kw OR 'physician'/de OR 'physician*':ti,ab,kw OR 'general practitioner'/exp OR 'general practitioner*':ti,ab,kw OR ' doctor*':ti,ab,kw OR 'family medicine':ti,ab,kw OR ‘family practitioner*’:ti,ab,kw | 1,039,039 |
| #1 AND #2: #3 | | 25,394 |
| #4 | 'deprescription'/exp OR ‘deprescri*’:ti,ab,kw OR ‘discontinu*’:ti,ab,kw OR ‘reconciliat*’:ti,ab,kw OR ‘withdrawal’:ti,ab,kw OR ‘decreas*’:ti,ab,kw OR ‘stop*’:ti,ab,kw OR diminution:ti,ab,kw OR cut:ti,ab,kw | 3,903,229 |
| #3 AND #4: #5 | | 4574 |
| Research strategy Web Of Science | | |
| #1 | “opiate*” OR “opioid*” OR “codeine “ OR “fentanyl” OR “tramadol” OR “oxycodone” OR “dihydromorph*” OR “buprenorphine” OR “hydrocodone” OR “morphin*” OR “metazocine” OR “pentazocine” OR “narcotic*” OR “analgesic*” | 249,684 |
| #2 | “primary medical care” OR “primary health care” OR “primary healthcare” OR “primary care” OR “first line care” OR “physician*” OR “general practitioner*” OR “doctor*” OR “family medicine” OR “family practitioner*” | 1,142,054 |
| #1 AND #2:#3 | | 13,170 |
| #4 | deprescription OR deprescri* OR discontinu* OR reconciliat* OR withdrawal OR decreas* OR stop* OR diminution OR cut | 4,545,936 |
| #3 AND #4:#5 | | 2,624 |
| Research strategy Cinahl | | |
| #1 | ((MH "Analgesics, Opioid") OR (MH "Morphine") OR (MH "Buprenorphine") OR (MH "Codeine") OR (MH "Oxycodone") OR (MH "Hydromorphone") OR (MH "Pentazocine") OR (MH “analgesic*”) OR (MH “opioid*”) OR (MH “opiate*”) OR (MH “narcotic*”) OR (MH “morphin*”) OR (MH “buprenorphin*”) OR (MH “MS contin”) OR (MH “MScontin”) OR (MH “codeine”) OR (MH “oxycodone”) OR (MH "Hydromorphone") OR (MH “hydromorphon*”) OR (MH "Pentazocine ") OR (MH “pentazocine”) OR TI(narcotics OR analgesics OR | 81,218 |

| | | |
|---|---|---|
| | opioid OR opioids OR opiates OR opiate OR tramadol OR remifentanil OR pentazocine OR oxycodone OR nalbuphine OR naltrexone OR methadone OR fentanyl OR dihydromorphinone OR codeine OR butorphanol OR buprenorphine OR alphaprodine OR “opioid peptides” OR “opioid peptide”) OR AB(narcotics OR analgesics OR opioid OR opioids OR opiates OR opiate OR tramadol OR remifentanil OR pentazocine OR oxycodone OR nalbuphine OR naltrexone OR methadone OR fentanyl OR dihydromorphinone OR codeine OR butorphanol OR buprenorphine OR alphaprodine OR opioid peptides OR opioid peptide)) | |
| #2 | ((MH "Primary Health Care+") OR (MH "Multidisciplinary Care Team+") OR (MH "Medical Care+") OR (MH "Rural Health Personnel+") OR (MH "Home Health Care+") OR (MH "Health Personnel+") OR (MH "Outcomes (Health Care)+") OR (MH "Health and Care Professions Council+") OR (MH "Physicians, Family+") OR (MH "Physicians+") OR (MH "Family Practice+")) OR TI(primary health care OR family practice OR TI primary care physician OR family doctor OR family doctors OR general practitioner OR general practitioners OR general practice) OR AB(primary health care OR family practice OR TI primary care physician OR family doctor OR family doctors OR general practitioner OR general practitioners OR general practice) | 1,187,829 |
| #1 AND #2:#3 | | 15,784 |
| #4 | (MH "Substance Withdrawal, Controlled") OR TI(deprescri* OR discontinu* OR reconciliat* OR withdrawal OR decreas* OR stop* OR diminution OR cut) OR AB(deprescri* OR discontinu* OR reconciliat* OR withdrawal OR decreas* OR stop* OR diminution OR cut) | 415,965 |
| #3 AND #4:#5 | | 2,776 |

APPENDIX B

| Section | Subsection | Quotes | Study |
|---|---|---|---|
| Barriers | | | |
| Patients’ fears | | *“I don’t think they’re aware of how bad withdrawals are. I mean there’s vomiting bile. There’s stomach cramps, there’s the cold shakes and fever. I mean it’s pretty bad. “* | Frank et al., 2016 |

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| | | *"I also had lots of fears about let's say there was an apocalypse in our society, what would happen to me? Where would I get my medication from? What was going to happen, you know? I would get so sick not having those drugs 'cause I was physically dependent on these drugs, you know. It's a very insecure feeling."* | Frank et al., 2016 |
| | | *"It sounds unnecessarily cruel and I don't think it will tell much. The group having their medication lowered are going to be in more pain why do you need a study to know that."* | James et al., 2019 |
| | | *"…patients felt threatened by the discontinuation and deprived of their medication and resented enduring trials to optimize alternate medication regimes."* | Chang et al., 2017 |
| | | *"Most patient fears involved the possibility of worse pain and withdrawal due to decreased opioids."* | Henry et al., 2019 |
| | | *"Most participants felt the need to make additional pain medications available to chronic pain sufferers, as they had exhausted alternative medications and therapies."* | Chang et al., 2017 |
| | | *"…assumption that pain will worsen as opioid medications are decreased and that no other substitute would be given to treat participants' pain."* | James et al., 2019 |
| Discordances in the patient provider relationship | Misinformation about tapering | *"Patients had varying ideas about what tapering meant; these ideas influenced attitudes about tapering and discussions with clinicians. Common synonyms for tapering were "cutting back," "reducing my medications," "weaning off," "going cold turkey," "detoxing," and "adjust[ing] down to nothing.""* | Henry et al., 2019 |
| | | *"Patients who used the terms "taper" and "detox" interchangeably tended to associate tapering with withdrawal symptoms."* | Henry et al., 2019 |
| | | *"She had me down from 10 to 5 [mg], and I didn't understand because I was still in the same amount of pain. I asked her and she said that a lot of people was OD'ing on pain medication and getting addicted. But I told her I was in a lot of pain, and this was not addiction. Because I do be in a lot of pain."* | Matthias et al., 2017 |
| | | *"…conveying understanding and negotiating about tapering were not always successful, and the result was conversations that could be contentious and frustrating."* | Matthias et al., 2017 |
| | | *"One patient expressed a lack of trust in the medication-related information provided by her physician at discontinuation because the physician had failed to inform her about OxyContin's properties at initiation."* | Chang et al., 2017 |

| | | | |
|---|---|---|---|
| | | *"Conflicting opinions among physicians and poor integration of medical services across healthcare professionals led to increased confusion about the medications."* | Chang et al., 2017 |
| | Communication and guidance problems | *"I just don't feel that he's understanding. He doesn't seem to care what I'm saying, because he's lowering it down anyway, even though I've told him that I didn't agree with it being lowered."* | Matthias et al., 2017 |
| | | *"They didn't really allow me to speak about anything or tell them anything: they just came in and looked at me really quick. (…) The thing is that the doctor just doesn't (…) want to listen to me about my pain. They just… it's like they thought that I was making it up or something just try to get the medicine. They made me feel like (…) I was an addict trying to get fixed."* | Al Achkar et al., 2017 |
| | | *"…physicians did not provide information on why OxyContin was discontinued or the range of alternative medications available, revealing communication gaps partially attributable to difficulty in accessing physicians."* | Chang et al., 2017 |
| | | *"My rheumatologist tells him not to change my medicine but he changes it anyway."* | Al Achkar et al., 2017 |
| | | *"I would like for [my doctor] to listen to me rather than listen to what my rheumatologist says to her, and how they communicate without me."* | Matthias et al., 2017 |
| | | *"I felt like, where did you go? When I attempted suicide, he checked on me daily and he made me sign a contract not to hurt myself and then here he is years later. Where did that loving, caring doctor go? I'm so loyal to you… I always looked to him for comfort and humor and caring and that just wasn't there. It was just this stranger sitting there."* | Henry et al., 2019 |
| | | *"Several patients reported experiences with clinicians who they perceived as focused on tapering opioids rather than treating pain: When you say you want to go down and get off of it, I'm making an initiative. He's not asking me to, and yet when I say, "Well, maybe I shouldn't have gone all the way off. At least maybe I should have something as a backup for when it's really, really bad." He comes back to me and says, "Uh, no, no. Sorry, we don't go backwards.""* | Henry et al., 2019 |
| | | *"I know some women that smoke pot and do other drugs and he's prescribing them pain meds and giving them drugs and not treating the women like he does the men. I just think that he is playing favoritism towards the women."* | Al Achkar et al., 2017 |

| | | | |
|---|---|---|---|
| The impact of government regulations on taking and reducing opioids | | *"I get drug tested about (every) 2 or 3 months. (…) I think it (the rules) made it more difficult for patients to get their medicines (…) it's hard to take off work to be able to go in every month or 2 months to the physician, whereas it used to be able to get refills every 3 to 4 months without having to go to the physician. (Now) it's usually every 6 weeks I see (the pain management) doctor."* | Al Achkar et al., 2017 |
| | | *"That kinda got me mad, cause I thought well you know. . .they're taking it off themarket because of people abusing it. . .It's not fair to us, you know. . . . I think the government was wrong to. . . pull them off the market, you know, because of people abusing them, no like they weren't looking at the people that need them. . .But I think it's really unfair that people that really do need them can't get them. "* | Chang et al., 2017 |
| The negative social influences and emotions around tapering | | *"My husband is very angry about this...I am so ashamed of this; I can't talk to anyone about it."* | Lee et al., 2019 |
| | | *"For example, one patient deferred tapering until after retirement because he needed opioids in order to work."* | Henry et al., 2019 |
| | | *"Changes in patients' health status also influenced their tapering experiences, often through new medical problems and repeat injuries. One patient reported starting, escalating, and then tapering off opioids 3 separate times; the last 2 episodes were due to injuries during car accidents."* | Henry et al., 2019 |
| | | *"[My doctor] treated me like I was a druggie or something, and I don't take anything that's not prescribed or more than is prescribed. I've been on [the opioids] for years and years, and what [another doctor] prescribed me, I wasn't even taking all of it. [Now the dose] is cut to less than half of what I used to take."* | Matthias et al., 2017 |
| | | *"I feel that people with chronic pain that have well tested and documented medical conditions causing the pain, are treated like addicted people and have high levels of pain daily that isn't treated properly. Sometimes opioids may be the only way to ease the terrible pain."* | James et al., 2019 |
| | | *"For other patients, emotional suffering resulted from the social stigma associated with opioid use. They perceived that stigma from media portrayals as well as from their PCPs. "* | Gruß et al., 2019 |
| | | *"If I go to my GP and admit it, what will happen? Will they take my baby away?"* | Lee et al., 2019 |
| | | *"I'm scared of going to my GP because I work with his wife and it will go down on my medical record."* | Lee et al., 2019 |
| | | *"There's a huge problem with heroin where I live, and the thought of queuing next to heroin users in my pharmacy fills me with horror. I suppose I'm not so different to them and it's just that my little addiction is a legal one."* | Lee et al., 2019 |

| | | | |
|---|---|---|---|
| | | *"That kinda got me mad, cause I thought well you know. . .they're taking it off themarket because of people abusing it. . .It's not fair to us, you know. . . . I think the government was wrong to. . . pull them off the market, you know, because of people abusing them, no like they weren't looking at the people that need them. . .But I think it's really unfair that people that really do need them can't get them. "* | Chang et al., 2017 |
| | | *"They didn't really allow me to speak about anything or tell them anything: they just came in and looked at me real quick. (…) The thing is that the doctor just don't (…) want to listen to me about my pain. They just… it's like they thought that I was making it up or something just try to get the medicine. They made me feel like (…) I was an addict trying to get fixed. "* | Al Achkar et al., 2017 |
| Problematic attitudes towards tapering | | *"[My doctor] treated me like I was a druggie or something, and I don't take anything that's not prescribed or more than is prescribed. I've been on [the opioids] for years and years, and what [another doctor] prescribed me, I wasn't even taking all of it. [Now the dose] is cut to less than half of what I used to take."* | Matthias et al., 2017 |
| | | *I was very upset.That's what I was. People who worked and had insurance companies that would pay for it can continue it. We are the lower part of the income scale. My option is OxyNEO, but I have to pay for it. I have no idea how much it is and if I have to pay for my occupational therapy, if I have to pay for my, what's its name to come and do my exercises, if I have to pay for, I mean this country that pays for your medication is not telling the truth.* | Chang et al., 2017 |
| | | *"I strongly believe in being on my opiate pain medication. When I was on it gave me the most normalcy to life. I was able to function, do daily activities, take care of my son, and be able to gain weight because my pain was all under control."* | James et al., 2019 |
| | | *"It sounds unnecessarily cruel and I don't think it will tell much. The group having their medication lowered are going to be in more pain why do you need a study to know that."* | James et al., 2019 |
| | | *"…after so long (pain medications) just seemed that they just didn't work; they were only making me tired (…) and the injections only lasted for 10, 15 min. By the time I made it to the car, it was over. (…) the injections, the medicated rub, pain relief rub, and Ibuprofen, Proxen, I've tried everything, you know? Cold packs for my knees and hot packs to my knee you know, they only work for a small period of time. "* | Al Achkar et al., 2017 |
| | | *"I've been on opiates, you know, for most of my adult life now, and I'm probably going to be on them for the rest of my life. I mean you're not going to cure what's wrong with me . . . so I'm always going to need something."* | Frank et al., 2016 |
| | | *"I needed help desperately by the time [hydrocodone] was prescribed for me . . . I had taken ibuprofen, Aleve, everything over the counter, and it did nothing to help me at all. So I knew I needed more help, stronger help."* | Frank et al., 2016 |

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| | | *"Absolutely not. Overdose? No. I'm very mature, very conscious, very intelligent as far as adhering."* | Frank et al., 2016 |
| | | *"The concern is that if they increase my opioid dosage, I could stop breathing. It's ridiculous."* | Frank et al., 2016 |
| | | *"I don't think people in chronic pain think about long term. We are basically, how do I get through today? I just gotta get through today."* | Frank et al., 2016 |
| Benefits | | | |
| Reducing pain medication does not equal increasing pain | | *"And surprisingly enough, my pain was actually lower on a smaller dose than a high dose."* | Gruß et al., 2019 |
| | | *"It's not much worse without the medication as it is with it. After you've taken it for a while, it doesn't do any good. That's what I've found. But that's hard to convince people of it. They look at me like I'm nuts, but it's true .. . I mean my pain is not any more severe than it was when I was taking all that stuff."* | Frank et al., 2016 |
| | | *"It hasn't affected me at all. In other words, I wouldn't know, uh, whether I am, by the way I feel, I can't tell, I wouldn't be able to tell whether I am still taking OxyContin, if I was in a blind taste test, not taste test but uh, blind medication administration test I suppose."* | Chang et al., 2017 |
| Improvement of quality of life in multiple dimensions | Resolution of negative side effects of chronic opioid usage | *"Tapering down was uncomfortable. They put me on like four different medications to kind of counteract that feeling. But I mean, my energy came back. Moods came back. I wasn't so down. I wasn't depressed. I wanted to do things. I felt like getting out more. And surprisingly enough, my pain was actually lower on a smaller dose than a high dose. And the only thing I can think of is when I was on a super-high dose, I did nothing but sit down and do nothing. And when I'm on a lower dose, I'm out doing things."* | Gruß et al., 2019 |
| | | *"And before I was on the pain killers, I was taking Aleve. And I went, you know, I wonder what would happen if I quit the pain killers and went back to taking Aleve. And within a few days my back quit hurting. My knees aren't hurting. My mind is much clearer because I'm not taking this stuff that…the pain killer that works on your mind. So I am doing so much better.* | Gruß et al., 2019 |
| | | *"I am more alert since I stopped taking [OxyContin], and I need less sleep, which is a blessing. So I'm able to do more things with my life."* | Frank et al., 2016 |
| | Improvement of social interactions | *"My family is really pleased too. Like, I'm more alert now. They say I'm engaged more again and talking to them. I don't just sit there and zone out."* | Frank et al., 2016 |
| Facilitators | | | |
| Awareness of problematic opioid usage and requesting help | | *"I realized that it was an addiction and I couldn't, I realized how I felt if I couldn't get to it...so I knew it was an addiction, and I knew I had to get off of them because that's not, my plan of life to live on addiction...so I decided that's it, I'm gonna do it on my own and I did."* | Chang et al., 2017 |

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| | | *"I'm struggling to say this, but I've got a painkiller addiction involving codeine. I really would like to get help but I'm unsure of how to do this. It's been going on for over three years now and is getting worse. I have to take two as soon as I wake and use two main brands, and this keeps on happening all day. I have attempted to stop two times before last year, but sickness and bad headaches stopped me. I am aware I am causing myself harm and know I should stop, but how? Ideas of how to stop would be really appreciated."* | Lee et al., 2019 |
| | | "*My name is...and I know I'm an addict. It's not an addiction to alcohol or street drugs and I've never smoked, but I am starting to realize I've got an addiction to painkillers."* | Lee et al., 2019 |
| | | *"I think the defining moment for me was, I was standing holding one of the babies and I fell asleep. My family had had it. They had had it so I wasn't allowed to see the kids, none of my grandkids, until I decided what I was going to do. …I didn't think that I had a problem. When I went to my first consultation with the rehab lady, I was like, this is not a problem until I detoxed. Once I detoxed, it was like, holy crap. This is a problem."* | Henry et al., 2019 |
| Individual incentives to taper | | *"I want to reclaim certain things in my life that were enjoyable, and I feel pain medication has altered."* | Henry et al., 2019 |
| | | *"I gotta lift myself up and I gotta push on. Sometimes I'll do it still under some pain, some stress, but I feel good on doing whatever I'm doing for the family or whatever it is that I need to keep pushing on and doing it 'cause once I eventually accomplish it, I feel great that I didn't let nothing hold me down and stop me from achieving things that I still—I can—achieve to do."* | Henry et al., 2019 |
| | | *"My life before I started the tapering process, I was kind of stuck in a box. I was on opiate medication I have to take regularly, I was more like a slave to it, and I basically there part of me said there's gotta be another way. (…) So, it pretty much, it does run your life."* | Henry et al., 2019 |
| | | *"I am concerned about using opioids as I age. I know that these drugs contribute to my foggy brain and that has gotten worse over the last year or so."* | James et al., 2019 |
| | | *"I hate what the medicine does to me."* | James et al., 2019 |
| | | *"I don't think any real patients enjoy the way they feel on opioids."* | James et al., 2019 |
| | | *"I think your body is just not meant to try to process that medication over a long period of time."* | Henry et al., 2019 |
| | | *"…after so long (pain medications) just seemed that they just didn't work; they were only making me tired"* | Al Achkar et al., 2017 |
| | | *"(Pain medications) would give me the shakes, not visual but the way I talked. My speech would be a little slurred and I just didn't like the effect."* | Al Achkar et al., 2017 |
| | | *"I really liked the haziness, and the pills helped with my stress and pain...but at work it meant I made little mistakes and couldn't focus. It wasn't that bad, but people thought I was lazy"* | Lee et al., 2019 |

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| Realization of the tapering process and taking responsibility | | *"It's a process, it's not something that you do one day and it's gone the next."* | Henry et al., 2019 |
| | | *"Understand that you are going to go through a lot of different changes [during tapering]. It's normal."* | Henry et al., 2019 |
| | | *"The reality of tapering off medication, for me, has been that if I'm careful, and I really follow the plan of taking a pill every six hours, or every eight hours, I'm going to be okay. … I may be somewhat physically uncomfortable, but I'm not in screaming pain. I'm in screaming pain when I've taken too much medication one day and don't have enough for the next day."* | Henry et al., 2019 |
| | | *"If you're struggling with your doctor, or struggling with the relationship with your doctor, I would first begin asking yourself, am I being completely honest with my doctor, and if I'm not, why not. That's a big question, because I found myself at times when I wasn't entirely honest with my doctor, and it was at the times when I pretty much wanted to medicate myself the way I wanted to medicate myself."* | Henry et al., 2019 |
| | | *"I just found different ways to cope with it, and to, I guess accept that, it's here to stay, and um, you just have to kind of figure out a way to, um, to try manage it and try, still have a bit of a life too...I guess the change just has to come from you just trying I mean myself just trying to, um, find a way through it or work around it."* | Chang et al., 2017 |
| Importance of good patient provider relationship as a means to successfully taper | Open communication | *"The best thing about it was that nobody acted like I was a bad person because I was on these medications and was having to be going through this really slow process of coming down off of them."* | Frank et al., 2016 |
| | | *"I did want to get off of them. I just didn't want to feel attacked with 'Hey, this is going to happen.' I wanted to go down. I didn't want to get off of it, but I was willing to go down, and I just felt [my health care provider] was there to help me, not to take something from me and bite me."* | Frank et al., 2016 |
| | | *"My doctor is very conscientious, and I respect her very much .. . OxyContin. I just quit cold turkey, which was difficult .. . She was overjoyed. She thought it was just great that I didn't need [OxyContin] anymore and that the steroid shots had helped me that much, so she was glad and so was I. We both high-fived over it."* | Frank et al., 2016 |
| | | *"I really felt like (the pain management doctor) and all of the team, they really did help me; they really did. They really did and got me on the way to where I need to be."* | Al Achkar et al., 2017 |
| | | *"The woman I had to wean, she accepted it. She said, 'You know, I don't think I did anything wrong. I used my own medication, but I understand what you have to do, and I think I'll be okay without them.' And that was kind of it."* | Matthias et al., 2017 |

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| | | *"She put me down to 2 and a half [pills per day]. Then she said, okay, we'll go down to half a pill. I told her I didn't think that just 2 a day would do it, and she said okay, we'll try 2 and a half, are you agreeable with that? I said that's fine. I mean, we can discuss stuff. It doesn't have to be a disagreement because we can talk about it. It's not an argument. We're 2 adults having a conversation, figuring out what to do."* | Matthias et al., 2017 |
| | | *"[my doctor] is very supportive. If I was in more pain, I feel like I could go back to her and say, 'I need more.'* | Henry et al., 2019 |
| | Having a safety net | *"I knew she wasn't just going to take me completely off of [the opioids] because I would be miserable... She just said, 'We'll try this, but if you need to go back to where you were, I'll do that.'"* | Matthias et al., 2017 |
| | | *"[my doctor] is very supportive. If I was in more pain, I feel like I could go back to her and say, 'I need more.'* | Henry et al., 2019 |
| Positive social and emotional influences | | *"The pills turned out horribly for me .. . I wasn't caring for myself. I wasn't bathing. I was sleeping all the time .. . Everything in my life was such a mess, and my husband was, you know, really worried about me .. . My husband [told me] that this is bad. This is really bad. You're not doing well."* | Frank et al., 2016 |
| | | *"It was very helpful 'cause there were times when I said I really wanted to go down, you know, like 2mg, and my husband would say, 'No, that's not a good idea .. . You're at 10mg. Let's not bump it to 8 after just 2 days. Let's wait and see what happens'. I knew I wasn't making good decisions [while on opioid medications] so my family was instrumental [during opioid tapering]. So, it wasn't just, you know, me being a strong woman and doing this. It was partnering with my provider, and my family being involved."* | Frank et al., 2016 |
| | | *"Like when a doctor tells them, get off these drugs, taper off these drugs, they might think the doctor just wants to do it to save money or save insurance costs ... Somebody who has been through it can say it really, really is true. It really happened to me. And maybe if I said, you know, I had these problems, maybe it would get them to open up. Maybe they would say, 'Yes, I had that problem too'."* | Frank et al., 2016 |
| | | *"You have to get people to people. On paper, [patients] don't care. They really don't. They have to have some one-on-one quality time with a real person who talks about real issues .. . It's almost like me or you watching TV. You don't know if that's a real person doing that or acting. You know, it's gotta be real. The doctors have got to really want to do this with these people, and you have to really find other patients that are willing to talk."* | Frank et al., 2016 |
| | | *"it's just that pain changes. It doesn't stay the same. Like everything, there's just constant change. It may take a while for it to change. It may get worse, it may get better."* | Henry et al., 2019 |
| Risks | | | |

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| Stressful patient provider relationship | Fear of losing normal care | *Henry et al. "Patients were often reluctant to challenge clinicians for fear of losing access to other medical services or of being labeled a "drug seeker."* | Henry et al., 2019 |
| | Switching clinicians | *"I decided that I needed to start tapering. And…brought it up with my doctor that I currently have. The one I have right before her. I ended it, because she told me that I would never be off of them, and she doesn't ever see me going off, and I just couldn't accept that. …So, I went and changed doctors."* | Henry et al., 2019 |
| Seeking "illicit" alternatives | | *I was just going to tell you to be honest with you. If I can't get my own script, then they are going to make me go out and ask for people, do you have any pain medicine? You know? I don't want to go that far.* | Matthias et al., 2017 |
| | | *"A few patients considered seeking alternative opioid sources during tapering when their pain or withdrawal was severe."* | Henry et al., 2019 |
| Unsupervised self-medication | | *" it doesn't take much to realize you need to hoard something … You have to take care of yourself, you have to advocate for your needs."* | Henry et al., 2019 |
| Opioid prescription restrictions as a trigger for emotional distress in patients | Fear of limited accessibility to opioids | *"The only thing I can think of would be more Vicodin. And he [PCP] says, you know, there are federal guidelines that keep us from giving more than x. And I haven't reached that level, yet. And I'm hoping I don't reach it, because I don't know what I'll do after that."* | Gruß et al., 2019 |
| | | *"I know what happened is the CDC came out with guidelines. And she [PCP] is following those guidelines, which is probably due to [the fact that the] management wants her to follow those. And I've read them too. And I don't agree with all of it. So, you know, I'm stuck basically. […] I mean, I'm to the point where I've considered changing my insurance to see if I can get another doctor that would allow it."* | Gruß et al., 2019 |
| | Negative influence on patient-provider relationship | *"This changed the patient's relationship from one where they felt heard and involved in the treatment process to one in which they felt controlled and treated in a more objective manner."* | Al Achkar et al., 2017 |
| | | *"Patients often used a passive voice when describing this change, seeing themselves as witnesses to the changes happening to them."* | Al Achkar et al., 2017 |
| | Reducing intake without thinking about the increase in complications | *"I was doing just fine (before the law change). Now I have to struggle, suffer, to make to the next time that I can get my medicine. And I don't think it's fair to me because if I can take my medicine a little more regularly, I would be able to do more and thought that we have a better effect in your life and I don't think that law, people, politicians, or anybody should be able to tell anybody that's in pain what type of medicine that they can take."* | Al Achkar et al., 2017 |

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| | | *"…the objectivity of the rule and accompanying testing changed the patient from a person in pain to a public health problem that needed to be objectively addressed."* | Al Achkar et al., 2017 |
| | | *"(The new law) messes up people that don't use drugs and the ones that do use it, that's on them. I don't put nothing in my body that's not prescribed by a doctor."* | Al Achkar et al., 2017 |

APPENDIX C

| STUDY | RESEARCH QUESTION | COUNTRY | NB | AGE | DATA COLL. | ANALYSIS METHOD |
|---|---|---|---|---|---|---|
| **[21]** | To characterize patients' experiences with opioid tapering and identify communication strategies that are likely to foster productive, patient-centered discussions of opioid tapering. | USA | 21 | Mean: 58.2 | Interviews and focus groups | Thematic analysis |
| **[22]** | To explore patients' perspectives on opioid tapering. | Denver, Colorado, USA | 24 | 52y (31y–73y) | Qualitative study using in-person, semistructured interviews. | Thematic analysis, mixed deductive and inductive approach |
| **[23]** | To explore experiences with opioid-related care under aggressive tapering efforts and concomitant heightened monitoring and institutional oversight among patients with chronic pain in an integrated delivery system through in-depth interviews. | USA | 97 | Mean: 61.3 | Interviews | Framework analysis |
| **[24]** | To understand communication processes related to opioid tapering, to identify best practices and opportunities for improvement | USA | 37 (patients) | Mean: 58 | Audio-recording and interviews | Thematic analysis |
| **[25]** | To evaluate the impact of Indiana's opioid prescription legislation on the patient experiences around pain management | USA | 9 (patients) | 43 - 73 | Semi-structured interviews | Thematic analysis |
| **[26]** | To explore the experiences of people with self-reported addiction to codeine and, specifically, how a social media forum is used to communicate with others about this issue. | UK, but online forum so | Not specified | Not specified | Selection and analysis of online posts and interactions on | Thematic analysis |

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| | | potentially international | | | Mumsnet, an online forum site. | |
| **[27]** | To gather perspectives on future research into opioid tapering from utilizers of chronic opioid therapy (COT) or other people affected by chronic noncancer pain | USA | 190 | | Questionnaires | Thematic synthesis |
| **[28]** | To capture the patients' experiences with discontinuing OxyContin, the efficacy of alternate medications, and relationships with physicians and to obtain physician perceptions on discontinuation | Canada | 13 | 45+ | Semi-structured interviews | Thematic analysis |

APPENDIX D

| **CRITERIA** | **STUDY**<br>**HENRY ET AL. (2019) [21]** | **FRANK ET AL. (2016) [22]** | **GRUß ET AL. (2019) [23]** | **MATTHIAS ET AL. (2019) [24]** | **AL ACHKAR ET AL. (2017) [25]** | **LEE ET AL. (2019) [26]** | **JAMES ET AL. (2019) [27]** | **CHANG ET AL. (2017) [28]** |
|---|---|---|---|---|---|---|---|---|
| Global quality rating | Moderate | Strong | Strong | Strong | Strong | Strong | Moderate | Strong |
| 1. Clear aims? | ✓ | ✓ | ✓ | ✓ | ✓ | X | ✓ | ✓ |
| 2. Qualitative methodology appropriate? | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| 3. Research design appropriate to address aims? | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | X | ✓ |

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| 4. Appropriate recruitement strategy? | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| 5. Data collection appropriate? | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| 6. Relationship between researcher and participants considered? | X | ✓ | ✓ | ✓ | ✓ | X | X | X |
| 7. Ethic issues into consideration? | X | X | ✓ | ✓ | X | ✓ | ✓ | ✓ |
| 8. Data analysis sufficientily rigorous? | X | ✓ | ✓ | ✓ | ✓ | ✓ | X | ✓ |
| 9. Clear statement of findings? | ✓ | ✓ | X | X | ✓ | ✓ | ✓ | ✓ |
| 10. Valuable research? | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |

APPENDIX E

| Summary of review finding | Example quote | Studies contributing to the review finding | CERQual assesment of confidence in the evidence | Explanation of CERQual aessessment |
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| Barriers | | | | |
| Patient's fears | *"I don't think they're aware of how bad withdrawals are. I mean there's vomiting bile. There's stomach cramps, there's the cold shakes and fever .. . I mean it's pretty bad." "* | Frank et al. 2016,<br>Al Achkar et al. 2017,<br>Chang et al. 2017,<br>Matthias et al. 2017,<br>Henry et al. 2019,<br>Lee et al. 2019,<br>James et al. 2019 | High confidence | Adequacy:<br>Very minor concerns<br>Relevance:<br>Minor concerns but high numbers of studies included.<br>Cohesion:<br>Minor concerns<br>Methodological limitations:<br>Moderate concerns in two studies |
| Discordances in the patient provider relationship | *"They didn't really allow me to speak about anything or tell them anything: they just came in and looked at me really quick. (…) The thing is that the doctor just doesn't (…) want to listen to me about my pain. They just… it's like they thought that I was making it up or something just try to get the medicine. They made me feel like (…) I was an addict trying to get fixed."* | Al Achkar et al. 2017,<br>Chang et al. 2017,<br>Matthias et al. 2017,<br>Henry et al. 2019,<br>Lee et al. 2019,<br>James et al. 2019 | High confidence | Adequacy:<br>Very minor concerns<br>Relevance:<br>Minor concerns but high numbers of studies included.<br>Cohesion:<br>Minor concerns<br>Methodological limitations:<br>Moderate concerns found in two studies |
| The impact of government regulations on taking and reducing opioids | *"I get drug tested about (every) 2 or 3 months. (…) I think it (the rules) made it more difficult for patients to get their medicines (…) it's hard to take off work to be able to go in every month or 2 months to the physician, whereas it used to be able to get refills every 3 to 4 months without having to go to the physician. (Now) it's usually every 6 weeks I see (the pain management) doctor."* | Al Achkar et al. 2017 | Low Confidence | Adequacy:<br>Major concern<br>Relevance:<br>Minor concern but only one study included.<br>Cohesion:<br>Minor concern<br>Methodological limitations:<br>No concerns but only one study included |

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| The negative social influences and emotions around tapering | *"There's a huge problem with heroin where I live, and the thought of queuing next to heroin users in my pharmacy fills me with horror. I suppose I'm not so different to them and it's just that my little addiction is a legal one."* | Al Achkar et al. 2017, Matthias et al. 2017, Chang et al. 2017, Henry et al. 2019, Lee et al. 2019, James et al. 2019, Gruß et al. 2019 | High confidence | Adequacy:<br>Very minor concerns<br>Relevance:<br>Minor concerns but high numbers of studies included.<br>Cohesion:<br>Minor concerns<br>Methodological limitations:<br>Moderate concerns in one study |
| Problematic attitude towards tapering | *"I've been on opiates, you know, for most of my adult life now, and I'm probably going to be on them for the rest of my life. I mean you're not going to cure what's wrong with me .. . so I'm always going to need something."* | Frank et al. 2016, Al Achkar et al. 2017, Matthias et al. 2017, Chang et al. 2017, James et al. 2019 | Moderate confidence | Adequacy:<br>Minor concerns, moderate concern in one study<br>Relevance:<br>Minor concerns but high numbers of studies included.<br>Cohesion:<br>Minor concerns<br>Methodological limitations:<br>Moderate concerns in two studies |
| Reducing pain medication does not equal increasing pain | *"And surprisingly enough, my pain was actually lower on a smaller dose than a high dose."* | Frank et al. 2016, Gruß et al. 2019, Chang et al. 2017 | Moderate confidence | Adequacy:<br>Moderate concerns<br>Relevance:<br>Minor concerns but only 3 studies included<br>Cohesion:<br>Minor concerns<br>Methodological limitations:<br>No concerns |

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| Resolution of negative side effects of chronic opioid usage | *"My mind is much clearer because I'm not taking this stuff that…the pain killer that works on your mind. So I am doing so much better."* | Frank et al. 2016, Gruß et al. 2019 | Moderate confidence | Adequacy:<br>Moderate concerns<br>Relevance:<br>Minor concerns but only two studies included<br>Cohesion:<br>Minor concerns<br>Methodological limitations:<br>No concerns |
| Improvement of social interactions | *"My family is really pleased too. Like, I'm more alert now. They say I'm engaged more again and talking to them. I don't just sit there and zone out."* | Frank et al. 2016 | High Confidence | Adequacy:<br>Minor concerns<br>Relevance:<br>Minor concerns but only one study included<br>Cohesion:<br>Minor concerns<br>Methodological limitations:<br>No concerns |
| Awareness of problematic opioid usage and requesting help | *"I'm struggling to say this, but I've got a painkiller addiction involving codeine. I really would like to get help but I'm unsure of how to do this."* | Chang et al. 2017, Lee et al. 2019, Henry et al. 2019 | Low confidence | Adequacy:<br>Moderate concern in one study<br>Relevance:<br>Moderate concern in one study<br>Cohesion:<br>Minor concerns<br>Methodological limitations:<br>Moderate concerns found in one study |
| Individual incentives to taper | *"I want to reclaim certain things in my life that were enjoyable, and I feel pain medication has altered."* | Al Achkar et al. 2017, Lee et al. 2019, James et al. 2019, Henry et al. 2019 | High confidence | Adequacy:<br>Moderate concern in one study<br>Relevance:<br>Minor concerns in one study<br>Cohesion:<br>Minor concerns<br>Methodological limitations: |

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| | | | | Moderate concerns found in two studies |
| Realization of the tapering process and taking responsability | *"It's a process, it's not something that you do one day and it's gone the next."* | Chang et al. 2017, Henry et al. 2019 | Low confidence | Adequacy:<br>Moderate concern in one study<br>Relevance:<br>Minor concerns<br>Cohesion:<br>Moderate concern in one study<br>Methodological limitations:<br>Moderate concern in one study |
| Open communication | *"I didn't want to get off of it, but I was willing to go down, and I just felt [my health care provider] was there to help me, not to take something from me and bite me."* | Frank et al. 2016, Al Achkar et al. 2017, Matthias et al. 2017, Henry et al. 2019, | Moderate confidence | Adequacy:<br>Moderate concern in one study<br>Relevance:<br>Minor concerns<br>Cohesion:<br>Minor concerns<br>Methodological limitations:<br>Moderate concern in one study |
| Having a safety net | *"[my doctor] is very supportive. If I was in more pain, I feel like I could go back to her and say, 'I need more.'"* | Frank et al. 2016, Matthias et al. 2017, James et al. 2019, Henry et al. 2019 | Moderate confidence | Adequacy:<br>Minor concerns<br>Relevance:<br>Moderate concern in one study<br>Cohesion:<br>Minor concerns<br>Methodological limitations:<br>Moderate concern in two studies |

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|---|---|---|---|---|
| Positive social and emotional influences | *"You have to get people to people. On paper, [patients] don't care. They really don't. They have to have some one-on-one quality time with a real person who talks about real issues .. . It's almost like me or you watching TV. You don't know if that's a real person doing that or acting. You know, it's gotta be real. The doctors have got to really want to do this with these people, and you have to really find other patients that are willing to talk."* | Frank et al. 2016, Henry et al. 2019 | Low confidence | <u>Adequacy:</u><br>Moderate concern in one study<br><u>Relevance:</u><br>Minor concerns but only two studies included<br><u>Cohesion:</u><br>Minor concerns<br><u>Methodological limitations:</u><br>Moderate concern in one study but only two studies included |
| Stressful patient provider relationship | *Henry et al. "Patients were often reluctant to challenge clinicians for fear of losing access to other medical services or of being labeled a "drug seeker."* | Henry et al. 2019 | Low confidence | <u>Adequacy:</u><br>Moderate concern<br><u>Relevance:</u><br>Minor concern but only one study included<br><u>Cohesion:</u><br>Minor concerns<br><u>Methodological limitations:</u><br>Moderate concern |
| Seeking "illicit" alternatives | *I was just going to tell you to be honest with you. If I can't get my own script, then they are going to make me go out and ask for people, do you have any pain medicine? You know? I don't want to go that far.* | Matthias et al. 2017, Henry et al. 2019 | Low confidence | <u>Adequacy:</u><br>Moderate concern in one study<br><u>Relevance:</u><br>Minor concerns but only two studies included<br><u>Cohesion:</u><br>Minor concerns<br><u>Methodological limitations:</u><br>Moderate concern in one study but only two studies included |

| | | | | |
|---|---|---|---|---|
| Unsupervised self medication | *" It doesn't take much to realize you need to hoard something … You have to take care of yourself, you have to advocate for your needs."* | Henry et al. 2019 | Low confidence | Adequacy:<br>Moderate concern<br>Relevance:<br>Minor concern but only one study included<br>Cohesion:<br>Minor concerns<br>Methodological limitations:<br>Moderate concern |
| Opioid prescription restrictions as a trigger for emotional distress in patients | *"I was doing just fine (before the law change). Now I have to struggle, suffer, to make to the next time that I can get my medicine. And I don't think it's fair to me because if I can take my medicine a little more regularly, I would be able to do more and thought that we have a better effect in your life and I don't think that law, people, politicians, or anybody should be able to tell anybody that's in pain what type of medicine that they can take."* | Chang et al. 2017,<br>Al Achkar et al. 2017,<br>Gruß et al. 2019,<br>James et al. 2019 | Low confidence | Adequacy:<br>Moderate concerns in two studies<br>Relevance:<br>Moderate concern in one study<br>Cohesion:<br>Minor concerns<br>Methodological limitations:<br>Moderate concern in one study |

# APPENDIX F – GOEDKEURING ETHISCHE COMMISSIE

## Patient perceptions on Tapering of Chronic Opioid Therapy

| | |
|---|---|
| **Dossiernr.:** | MP016984 |
| **Masterproef:** | Masterproef I HAIO, 2019-2022 |
| **Faculteit/opleiding:** | Faculteit Geneeskunde - Master in de huisartsgeneeskunde |
| **Studiefase:** | eerste fase |
| **Academiejaar:** | 2020-2021 |
| **Korte omschrijving / abstract:** | Recente cijfers tonen aan dat opioïdengebruik in België alomtegenwoordig is. 10% van de bevolking heeft het afgelopen jaar een opioïde afgehaald bij de apotheker. Chronisch gebruik heeft echter grote nadelen, met bijwerkingen en afhankelijkheid als gevolg. Als artsen komen ook wij regelmatig in contact met opioïden. Onze taak bestaat er deels in om patiënten die gedurende lange tijd een fysieke afhankelijkheid hebben voor sterke pijnmedicatie (i.e. opioïden) te kunnen herkennen. Deze patiënten zich hier bewust van maken alsook een plan opstellen om deze medicatie af te bouwen vormt een van de moeilijkere taken voor elke arts. Het leek ons daarom interessant om na te gaan wat de percepties van de patiënten zijn met betrekking tot het afbouwen van opioïden. Aan de hand van een systematische review proberen we in beeld te brengen of er mogelijke misvattingen zijn, waar de heikelpunten liggen en welke kennis er reeds is. Op deze manier hopen wij een beter algemeen beeld te krijgen wat betreft het afbouwen van opoïden alsook kernpunten herkennen waar wij als artsen op zouden kunnen inspelen om het proces te doen slagen. |
| **Opmerkingen / praktische informatie:** | Meta-synthese: Deze studie zullen we uitvoeren aan de hand van de beschikbare literatuur in de online databanken (Pubmed, Cinahl, WOS, Embase). Op basis van relevantie van de titels en abstracten zullen we een bepaald aantal studies includeren. Deze studies zullen eveneens geselecteerd worden op basis van wetenschappelijke kracht, met voorkeur voor RCT's. |
| **Toegepaste technieken:** | Meta-synthese |
| **Gewenste taal van communicatie:** | en |
| **Promotor:** | Professor Cathy Matheï (u0009104) |
| **Organisatie:** | KU Leuven |
| **Dienst:** | Academisch Centrum voor Huisartsgeneeskunde |
| **Discipline:** | Masterproef |
| **Extra groepsleden:** | Edwin Michalik<br>edwin.michalik@student.kuleuven.be<br>r0264326 Ward Lettens<br>ward.lettens@student.kuleuven.be<br>r0597380 Emma Leeuws<br>emma.leeuws@gmail.com<br>r0854690 Lucas Claessens<br>lucas.claessens@student.kuleuven.be<br>r0675968 |

De verstrekte informatie toont aan dat het onderzoek in het kader van de masterproef een zuivere literatuurstudie betreft en dat er op geen enkele wijze gebruik wordt gemaakt van proefdieren, proefpersonen of menselijk lichaamsmateriaal.

Dit type onderzoek vereist geen goedkeuring van een gemachtigde commissie voor medische ethiek.

Onder voorbehoud van de volledigheid en correctheid van de door u verstrekte gegevens, krijgt u hierbij het akkoord om het onderzoek in het kader van de masterproef te starten. Deze mail dient als bewijs van goedkeuring mocht u uw onderzoek wensen te publiceren.

# Persoonlijke reflectie Masterproef – Classens Lucas

Eerst zou ik het verloop van het groepsproces willen bespreken van de afgelopen 3 jaren. Een masterproef schrijven tijdens deze periode van ons leven vormde voor mij toch een uitdaging. De combinatie werk, school, sociaal en masterthesis was niet te onderschatten. Het opstarten van de masterproef verliep toch wel stroef in de beginfase aangezien we met vieren moesten samenwerken ieder met zijn eigen verantwoordelijkheden en levens. Tijdens de beginfase (januari 2020) moesten we in samenspraak met prof. dr. Matheï een onderwerp kiezen. We kozen allen voor een systematic review, dat uiteindelijk een meta-synthese werd. Wij (Edwin, Emma, Ward en ik) en ook Prof. Matheï hadden geen ervaring met deze onderzoeksvorm. We kwamen daardoor traag op gang. We hadden enorm veel aan prof. Matheï en gaf duidelijk aan wat ze van ons verwachtte en wat we allemaal moesten doen. We begonnen eerst met het maken van de methodologie en de zoekstrategie. De zoekstrategie maakten we samen met een medewerkster met de universiteitsbibliotheek die ons in de juiste richting stuurde. Na het afronden van de zoekstrategie bundelde we alle gevonden artikels en gaf Prof. Matheï in augustus 2020 ons groen licht voor de selectieprocedure. Deze procedure duurde tot november 2020 waarna prof. Matheï een maand de tijd vroeg voor een presentatie voor te bereiden voor het uitvoeren van een meta-synthese en deze ging ze aan ons voorstellen december 2020. Echter werd prof. matheï ziek waardoor we toch wat moeilijkheden ondervonden om verder te gaan. Ondertussen verzocht ze ons te starten met de line-by-line coding via het programma Nvivo aan de hand van een youtube video en meerdere voorbeeld artikels. Dit proces verliep heel moeizaam en we vernamen dan ook dat Prof. Matheï ernstig ziek was en vervolgens kwam ze te overlijden. We kregen vervolgens Prof. Dr. Aertgeerts aangewezen als promotor en co-promotoren Trudy Bekkering en Kristien Coteur toegewezen. Onze thesis kwam na een initiële zoomsessie terug op gang waarna we onder verdere begeleiding de introductie verder aanpasten, de methodologie verder afwerkten en begonnen aan de line-by-line coding. Hier zijn vele zoomsessies voor nodig geweest om dit adequaat uit te voeren. We verdeelden al het werk in duo's van twee, meestal werkten Edwin & Emma samen en werkten Ward en ik samen. Wanneer we klaar waren met een opdracht kwamen we vervolgens online samen en bespraken alles in groep. Tijdens het schrijven van de resultaten deed iedereen zijn eigen deel. Naarmate de thesis verder vorderde deden we steeds meer met vieren. We schreven dan ook het abstract, discussie en conclusie met vieren. Dit zorgde er dan wel voor dat we vaak moesten samen komen en we vaak lange avonden achter onze computer zaten. De groepsdynamiek zat dan ook goed en hebben alles vlot kunnen afwerken. Ik denk dat het dan ook een zeer goede samenwerking was en we het samen goed hebben aangepakt desondanks onze drukke agenda's en de wereldwijde pandemie. We hadden ook

enorm veel aan onze promotoren die altijd klaar stonden voor het beantwoorden van onze vragen en het sturen van onze thesis.

Vervolgens zou ik meer willen vertellen over mijn persoonlijk aandeel. Vanaf het begin heb ik geprobeerd om in te staan voor een goede communicatie tussen ons en de promotoren. In de beginfase was dit niet zo vanzelfsprekend omdat we traag op gang kwamen en we niet veel vooruitgang maakten. In de beginfase verzorgden Ward en ik de zoekstrategie in constant overleg met prof. Matheï en bundelden we de gevonden artikels in het programma Rayann. Na het initiële ontwerp van de introductie door Emma, vertaalden we deze naar het Engels en pasten we deze verder aan. Vervolgens zorgde Ward voor het verder perfectioneren van de introductie. We werkten daarna in groepjes van twee (Edwin & Emma, Ward en ik) om per duo 2863 artikels te screenen op titel/abstract. Tegelijkertijd deed Emma ook enorm veel werk op vlak van de controle van de gevonden artikelen en spitte ze samen met Edwin de verschillende scoresystemen uit om de artikels juist te evalueren. Na het afronden van de introductie en methodologie, zijn we samen gestart met het line-by-line coding in de gekende duo's en bundelden we deze in het programma NVivo. In consensus vertaalden we deze codes naar analytische thema's en schreven we ieder ons deel in de resultaten. Ikzelf schreef het laatste deel van de facilitatoren en het volledig deel van risico's. Uiteindelijk schreven we allemaal samen in meerdere zoomsessie het abstract, discussie en conclusie. Verder hield ik me ook bezig met de referenties op de juiste plaats te zetten. En zorgden ik ervoor dat onze promotoren op de hoogte bleven van onze vorderingen.

Mijn persoonlijke visie over ons werk en de betekenis voor het werkveld is dat het een zeer relevant werk is voor verder toekomstig onderzoek en zelfs op dit moment al artsen kan helpen in het afbouwproces van opioïden. Het opioïden probleem aanpakken is een enorme uitdaging en is iets waar we samen met alle hulpverleners werk van moeten maken. Het is dan ook heel erg belangrijk om naar de patiënt te luisteren en niet zelf unilateraal te beslissen voor de patiënt. We moeten nog meer onze patiënt leren begrijpen en echt begeleiden in dit proces door de positieve perspectieven te belichten zodat we ervoor kunnen zorgen dat we de patiënten niet verder ook onbewust stigmatiseren als 'verslaafden'. We moeten individuele plannen opstellen en blijven informeren zodat we dit probleem kunnen oplossen.

Het was een enorm interessante en leerrijke ervaring om met onze groep deze thesis te schrijven. Ik wil daarom ook mijn collega's Edwin, Emma en Ward enorm bedanken voor de samenwerking. Ik bedank ook in het bijzondere prof. dr. Matheï die helaas te vroeg van ons is heengegaan voor de bijzonder leerrijke contacten. Prof. dr. Aertgeerts, Trudy Bekkering en Kristien coteur wil ik ook graag bedanken voor deze ervaring.

# Persoonlijke reflectie masterproef – Leeuws Emma

Allereerst zou ik graag het verloop van het groepsproces en de samenwerking met mijn collega huisartsen in opleiding bespreken. Niet elk groepswerk is een voltreffer. Het is een uitdaging om met meerdere persoonlijkheden een gemeenschappelijk doel te bereiken. Er wordt van iedereen een eigen inbreng verwacht en deadlines moeten nagekomen worden. Voornamelijk in de beginfase van ons groepsproject werden deadlines niet altijd (meteen) nagekomen, echter na verloop van tijd is er een bepaalde routine gekomen en verliep het groepsproces zeer goed. Elke huisarts in opleiding had zijn eigen inbreng en elke persoon toonde inzet. Naar het einde toe werden de overleg momenten steeds frequenter en werd onze masterproef echt een gezamenlijk project. Gezien de corona crisis gingen de 'samenkomsten' steeds online door. Dit voelde niet aan als een minpunt, gezien hierdoor de pendeltijd beperkt kon worden en er frequenter kon overlegd worden, ook na een drukke werkdag.

Dit groepswerk was gelukkig een voltreffer. Er was een gezonde en goede groepsmentaliteit en dit heeft geleid tot het eindresultaat waarvan ik zeer tevreden ben. Ik apprecieer mijn collega's huisarts in opleiding (Lucas Claessens, Ward Lettens en Edwin Michalik) en weet dat niet elk groepsproces zo vanzelfsprekend soepel verloopt.

Vervolgens wil ik uitweiden over mijn persoonlijk aandeel in het groepsproces. Elke samenkomst heb ik een persoonlijke inbreng gebracht. Ik stelde mee doelen op en reflecteerde samen met mijn groepsgenoten. Ik haalde elke deadline en stelde ook mee deadlines op. Wat de thesis zelf betreft; ik was mee verantwoordelijk voor de eerste versie van de inleiding (via trechtervorm) en de methodologie (via ENTREQ). Bij de afwerking van de methodologie heb ik een onderdeel voor mijn rekening genomen. Samen met mijn groepsgenoten heb ik via Rayyan mee artikelen geselecteerd. Verdere selectie vanuit full text en toepassen van de CASP criteria heb ik samen met Edwin gedaan. Ik heb samen met Edwin de kenmerken van de geselecteerde artikelen samengevat in een tabel. Verder heb ik, net zoals mijn collega's huisarts in opleiding, line by line coding toegepast op onze geselecteerde artikelen. Na deze line by line coding hebben we in gemeenschappelijk en herhaaldelijk overleg algemene beschrijvende thema's vastgelegd. Vervolgens na verdelen van de thema's, schreef ik een groot deel van de facilitators en het volledige benefits gedeelte. Aanpassing van deze delen bij eventuele opmerkingen van de (co-)promotoren, was ook mijn verantwoordelijkheid. Ik was meestal aanwezig bij overleg, tenzij bij onvoorziene omstandigheden. In gemeenschappelijk overleg, gaande over verschillende sessies, werd de discussie geschreven. Kleine aanpassingen in abstract en conclusie waren ook mijn inbreng. Vaststellen van de confidence in findings via het GRADE cerqual scoresysteem was een gedeelde taak waarin ik ook mijn

bijdrage heb geleverd. De uiteindelijke afwerking van de volledige thesis op basis van feedback van de copromotoren gebeurde steeds in groep.

Tenslotte wil ik graag mijn persoonlijke visie op de thesis toelichten. Allereerst wil ik herhalen dat ik zeer tevreden ben van het eindresultaat. Bij de selectie van de mogelijke thesis onderwerpen, was ik meteen geïntrigeerd door de onderzoeksvraag. Het leek mij zeer relevant, aangezien ik zelfs in mijn korte ervaring als huisarts in opleiding reeds geconfronteerd was met chronisch opioïden gebruik (en misbruik) bij niet-kanker patiënten. Het is een relevant en veelvoorkomend probleem in de huisartsenpraktijk, maar het is eveneens een maatschappelijk probleem. Er zijn handvaten beschikbaar voor artsen voor de aanpak van afbouw van chronisch opioïden gebruik, maar meestal wordt het effect van de vermindering benadrukt eerder dan de ervaring van de patiënt. Richtlijnen op de Nederlandse website NHG zijn recent toegevoegd, maar algemeen blijken ze meer op consensus gebaseerd dan op werkelijk wetenschappelijk onderzoek. Wetenschappelijk onderzoek over de perspectieven van patiënten betreffende de afbouw van chronisch opioïdengebruik is schaars, getuige ons beperkt aantal gevonden relevante artikelen. Via onze masterproef worden de ervaringen van patiënten gebundeld via een thematische analyse. Mijn ervaring met thematische analyse was onbestaande voor dit project, desondanks ben ik van mening dat het een interessante invalshoek is en een belangrijk perspectief kan bieden voor relevante onderwerpen. Het was een verrijking voor mijn persoonlijke ontwikkeling om een dergelijk proces van begin tot eind mee te maken. Ik ben ervan overtuigd dat deze thesis een bijdrage kan betekenen voor het verbeteren van de huidige richtlijnen. Een belangrijk aspect voor het succesvol afbouwen van chronisch opioïdengebruik, blijkt de band tussen arts en patiënt. Door te focussen op de perspectieven van de patiënt, kan de manier van communiceren aangepast worden en kan de kans op succes vergroot worden.

De resultaten van deze meta-synthese zal in ieder geval mijn persoonlijke aanpak als arts beïnvloeden bij vaststelling van chronisch opioïden gebruik bij patiënten zonder kanker. Door het positieve te benadrukken, niet te stigmatiseren, voldoende te informeren en samen met de patiënt een plan op te stellen zal de patiënt sneller geneigd zijn de arts te vertrouwen en een afbouwproces aan te vangen. Dit zal de band tussen de patiënt en de arts enkel ten goede komen.

Afsluiten wil ik door mijn collega huisartsen in opleiding en de (co)promotoren te bedanken voor het verrijkende en interessante proces. Ook wil ik professor dr Cathy Matheï bedanken, zonder wie deze thesis er niet zou geweest zijn.

# Persoonlijke reflectie Masterproef – Lettens Ward

De voorbije 3 jaren hebben wij met 4 personen samengewerkt aan deze thesis. Lucas, Emma, Edwin en ikzelf woonden ten eerste al zeker niet bij elkaar in de buurt, wat de samenwerking wel uitdagend maakte. We kozen er dan ook voor om onze meetings telkens online te doen, via Zoom sessies. Dit was tevens praktisch gemakkelijker voor onze wijlen promotor Prof. Dr. Cathy Matheï. In het eerste jaar spraken we af om de 2 à 3 maanden. Naargelang de jaren en de thesis vorderden nam de frequentie toe naar maandelijks en uiteindelijk wekelijks tot meerdere keren per week in de laatste fase van de thesis.

Initieel vorderde de thesis wat stroef. We waren in het begin nog onzeker over hoe we de thesis als groep gingen aanpakken, alsook het onderwerp lag nog niet definitief vast. In samenspraak met Prof. Matheï gingen we uiteindelijk een thesis schrijven over 'Percepties van patiënten bij het afbouwen van opioïden'. Ze gaf ons aan dat we de thesis moesten schrijven in de vorm van een meta-synthese in plaats van een systematic review, wat het oorspronkelijke plan was. Voor elk van ons was een meta-synthese een nieuw concept en hadden we totaal geen idee hoe dit in elkaar stak. Ons onderwerp was tevens gebaseerd op percepties van patiënten in plaats van ruwe data, waardoor we andere databases moesten raadplegen dan we gewoon waren.

Tijdens ons eerste HAIO-jaar hebben we een lange tijd geworsteld met het formuleren van een correcte onderzoeksvraag en het schrijven van een adequate methodologie. Een andere grote uitdaging was het genereren van een goede zoekstrategie. We hebben lang gezocht naar de juiste hoofdtermen (Mesh termen) om in te geven in de databases gezien we vaak op een zeer beperkt aantal studies uitkwamen. Onder begeleiding van Prof. Matheï en een medewerkster van de universiteitsbibliotheek is dit ons uiteindelijk gelukt en kregen we groen licht om in ons tweede jaar te beginnen aan het verwerken van de gevonden artikels (duplicaten verwijderen, selecteren en lezen van artikels,…). Uiteindelijk hadden we nog steeds een beperkt aantal artikels, maar in overleg met Prof. Matheï zijn we hier toch mee aan de slag gegaan want dit opende de deur naar eventueel verder onderzoek.

In ons tweede HAIO-jaar heeft ons werk gedurende langere tijd stilgelegen. Na het afronden van het initiële werk zou Prof. Matheï ons een opleiding geven over hoe je juist een meta-synthese opbouwt en verder moet uitwerken. Na wat gemiste afspraken waren we enkele maanden verder en kregen we een mailtje van Prof. Matheï dat ze gedurende een lange tijd afwezig ging zijn. We kregen de opdracht om zelf in de literatuur op te zoeken hoe je een meta-synthese uitwerkt. We moesten gebruik maken van 'Line-by-line coding' via het programma Nvivo ®. Ze had ons ook een video doorgestuurd waarin dit in grote lijnen uitgelegd werd.

Jammer genoeg kregen we niet veel later te horen dat Prof. Matheï overleden was. Het duurde daarna enige tijd vooraleer onze thesis terug wat op gang kwam. We pikten de draad terug op,

in de lente van ons tweede HAIO-jaar, onder begeleiding van onze nieuwe promotor Prof. Dr. Bert Aertgeerts en co-promotoren Trudy Bekkering en Kristien Coteur. Na een kennismakingssessie via Zoom en een korte samenvatting over hoe ver we stonden, werden we eerst wat aan de tand gevoeld vanwege het kleine aantal artikels dat we hadden vergaard. Na een heldere uitleg was uiteindelijk iedereen op de hoogte van de stand van zaken m.b.t. de thesis en kregen we al snel terug een plan van aanpak.

Over het algemeen hebben we het gros van het werk gezamenlijk verzet. Gezien we enkel online konden afspreken via Zoom hebben we het meeste schrijfwerk samen afgewerkt. Na elke sessie werden dan de taken evenredig verdeeld, meestal deden we dit in duo's. Tijdens deze sessies bespraken we dan de gevonden resultaten in groep. Op deze manier hadden we iedere keer een deadline wat maakte dat er een beetje groepsdruk was en de thesis toch adequaat vorderde. Aan de andere kant had deze aanpak tot gevolg dat de Zoom sessies vaak lang duurden gezien we veel discussieerden vooraleer we tot een consensus kwamen. Deze bevindingen werden dan ook onmiddellijk, tijdens de Zoom sessies, aangepast in ons werk. Achteraf gezien kan ik dus zeker stellen dat onze samenwerking heel goed was en we allemaal ongeveer evenveel inbreng hadden.

Ik heb mij tijdens het eerste anderhalf jaar vooral beziggehouden met het afwerken van de introductie (initieel geschreven door Emma) en het eerste stukje van de methode. Lucas en ik hebben de zoekstrategie uitgewerkt en ingegeven in de 4 verschillende databases. Het verwijderen van duplicaten, alsook het selecteer werk (eerst via Titel/abstract, nadien via het lezen van de artikels) hebben we eerst elk apart gedaan en nadien zowel in duo's als nog eens gezamenlijk overlopen. Via consensus zijn we dan tot ons finaal aantal artikels gekomen. Vervolgens hebben we ons verdeeld in 2 groepen voor het 'Line-by-line' coderen van de artikels, dewelke we nadien opnieuw als groep hebben overlopen en samen hebben gezet (in Nvivo®) om tot analytische thema's te komen. Deze thema's vormden in principe de hoofdtitels van onze thesis. Het beschrijven van de resultaten, met de analytische thema's als leidraad, hebben we dan elk apart gedaan. Ieder had zijn evenredig stukje dat hij/zij moest beschrijven. Ik heb het stukje geschreven over barrières van 1.1 tot 1.3. Nadien hebben we de resultaten opnieuw gezamenlijk overlopen om er een mooi geheel van te maken. Ten slotte hebben we samen de discussie en de conclusie geschreven. Dit gebeurde continu in overleg met onze co-promotoren dewelke via mail feedback gaven.

Onze thesis is zeker interessant om te gebruiken in het werkveld. Het geeft in de eerste plaats een beeld aan artsen over hoe patiënten omgaan met het afbouwen van opioïden, hetgeen soms moeilijk in te schatten is. Bijgevolg kunnen we hiermee ook tips of aanbevelingen bieden aan (huis)artsen om er beter mee om te gaan en zo het succes van het afbouwen van opioïden te bevorderen.

Ten tweede opent deze studie ook deuren naar verder onderzoek over deze kwestie. Gezien de samenhang met verslavingsproblematiek (cfr discussie) zijn er zeker nog opties om dit verder te bestuderen. Bovendien bestaat er niet zo veel literatuur over het onderwerp van onze thesis, wat te zien was aan het beperkt aantal gevonden artikels. Dit geeft aan dat verder onderzoek naar deze percepties aan de orde is om deze hopelijk later in de huidig bestaande richtlijnen te integreren.

# Persoonlijke reflectie Masterproef – Michalik Edwin

Tijdens de driejarige master Huisartsgeneeskunde hebben we met vier groepsleden (Lucas Claessens, Ward Lettens, Emma Leeuws en Edwin Michalik) gewerkt aan onze Manama thesis. Deze thesis is een meta-synthese rond de percepties van patiënten met betrekking tot het afbouwen van legale opioïden bij chronisch gebruik in een niet-kanker gerelateerde eerstelijnssetting.

In het begin van de opleiding moest iedereen individueel keuzes doorgeven qua onderwerp en werkvorm. Ik koos voor een literatuurstudie (systematic review), gezien zowel mijn bachelor- als mijn masterthesis literatuurstudies waren en ik mij hiermee meer vertrouwd voel dan veldonderzoek. Initieel had ik gekozen voor een systematische review rond de percepties van patiënten rond het afbouwen van benzodiazepines. Echter was dit onderwerp al toegewezen aan andere HAIO's, en in overleg met de groepsleden en wijlen Prof. Dr. Cathy Matheï hadden we het onderwerp, alsook de werkvorm, veranderd.

De start van de thesis liep niet zo gemakkelijk gezien samenwerken met vier meer coördinatie met zich meebrengt, en gezien onze opleidingsplaatsen over het gehele Vlaamse grondgebied verspreid zijn, waardoor we nooit fysiek konden samenzitten. Een meta-synthese schrijven was ook anders dan een systematic review, waardoor het in het begin voor ons – maar ook voor prof. Matheï – zoeken was naar de juiste aanpak. Wij alle vier hadden nauwelijks ervaring met het werken met kwalitatieve data, noch de gebruikte databanken.

Prof. Matheï heeft ons in het begin proberen duidelijk te maken wat er verwacht werd en we begonnen met het opstellen van onze methodologie en de zoekstrategie. Voor dit laatste kregen we hulp van een medewerkster van de universiteitsbibliotheek 2Bergen, KU Leuven (Mevrouw Kristel Paque). We besloten te schrijven in de Engelse taal, omdat we vermoedden dat de meeste bronnen Engelstalig zouden zijn en we de kwalitatieve data zo beter konden gebruiken (i.p.v. te moeten vertalen). Het opstellen van de zoekstrategie was niet gemakkelijk, maar na veel overleg hadden we een goede query opgebouwd. Deze leverde ons in totaal, na verwijderen van de duplicaten, bijna 6.000 resultaten op.

We gingen dan aan de slag met het selecteren van de relevante artikels. We splitsen ons in twee groepen (Lucas-Ward en Emma-Edwin) en we namen per groep de helft van de artikels voor onze rekening. Van deze selectie (een 35-tal artikels) maakten Emma en ik een overzicht van de belangrijkste eigenschappen en er werd dan verder geselecteerd op basis van de volledige tekst. Uiteindelijk hielden we hierdoor slechts acht artikels over. Dit toonde meteen

aan dat het gekozen onderwerp nog niet zoveel aandacht had gekregen, en dat onze meta-synthese zeker een basis zou kunnen vormen voor verder onderzoek. We kregen van prof. Matheï de toestemming om met dit beperkte resultaat verder te werken. Ze zou ons een opleiding geven over de verdere aanpak van een meta-synthese.

Echter werd prof. Matheï ernstig ziek en was ze niet meer in staat ons verder direct te begeleiden. Ze gaf ons instructies om verder op te zoeken hoe een meta-synthese wordt uitgevoerd (o.a. via voorbeeldartikels en YouTube®). Ze stuurde ons instructies rond line-by-line coding met behulp van NVivo®. We vernamen echter niet veel later dat prof. Matheï overleden was. Dit nieuws sloeg in als een bom, en onze thesis lag toen een tijdje stil.

We hernamen onze thesis tijdens het eerste contact met onze nieuwe promotor Prof. Dr. Bert Aertgeerts en copromotoren Mevrouw Trudy Bekkering en Mevrouw Kristien Coteur. Bij dit eerste contact gaven we duiding omtrent waar we stonden met de thesis en wat oorspronkelijk de bedoeling was (zoals afgesproken met prof. Matheï).

Vervolgens analyseerden Emma en ik de kwaliteit van de overgebleven artikels met de Critical Appraisal Skills Programme (CASP®) checklist voor kwalitatief onderzoek. Ondertussen schreven we verder aan de introductie, en we maakten updates in de methodologie. Voor de line-by-line coding in NVivo® werkten we in dezelfde duo's als voorheen, waarbij we elk de helft van de artikels codeerden.

We legden onze resultaten op regelmatige basis samen, en vanaf nu begonnen we ook regelmatiger af te spreken op Zoom®. We begonnen onze codes onder te verdelen in grote categorieën, en op basis van deze verdeelden we het werk om de resultaten te verwerken en in een tekst te gieten. Ikzelf heb met Ward de barrières voor rekening genomen. We legden onszelf deadlines op zodat onze thesis vooruitging, en kwamen geregeld samen om de resultaten te overlopen en feedback te geven aan elkaar omtrent hetgeen we geschreven hadden en we pasten de tekst in onderling overleg aan. We begonnen nu ook regelmatiger tussentijdse resultaten door te sturen naar onze begeleiders, en startten aan onze discussie en conclusie. Deze laatste twee hebben we integraal met ons vier tezamen geschreven, waarbij we regelmatig versies doorstuurden naar onze begeleiders voor feedback.

Doordat we progressief meer delen met ons vieren tezamen deden, leidde dit vaak tot lange zoomsessies. Dit was zeker niet evident in combinatie met lange werkdagen en de extra druk door de pandemie. De samenwerking over Zoom® viel heel goed mee, net als het overleg met de begeleiders.

Het verbaasde ons doorheen het project hoe weinig literatuur beschikbaar was omtrent dit onderwerp. Dit motiveerde ons eens te meer om een zo goed mogelijk project af te werken, en het is onze hoop dat deze studie enkele handvaten kan aanreiken voor de klinische praktijk, en een aanzet geeft naar bijkomend onderzoek. Dit was ook de wens van prof. Matheï.

Tot slot wil ik een woord van dank uiten. In de eerste plaats dank ik mijn echtgenote, Zheyun, en onze zoon, David. Zij hebben me regelmatig moeten missen, en de combinatie met het werk maakte het niet eenvoudig voor hen. Ik wens ook mijn thesispartners te danken voor hun inzet, maar ook vooral hun geduld richting mij. Ik had omwille van persoonlijke redenen, waar ik hier niet verder op in ga, voor een korte periode niet de mogelijkheid actief deel te nemen aan de thesis. Uiteindelijk was ik wel terug veel actiever geworden, na een gesprek met mevr. Bekkering. Ik wens haar, mevr. Coteur en prof. Aertgeerts te bedanken voor hun begeleiding. Mijn, en ik denk dat ik kan spreken voor de volledige groep, gedachten gaan uit naar prof. Matheï en haar nabestaanden. Zij is veel te vroeg heengegaan. Een speciaal woord van dank gaat dan ook uit naar haar voor ons op weg te helpen in deze thesis.