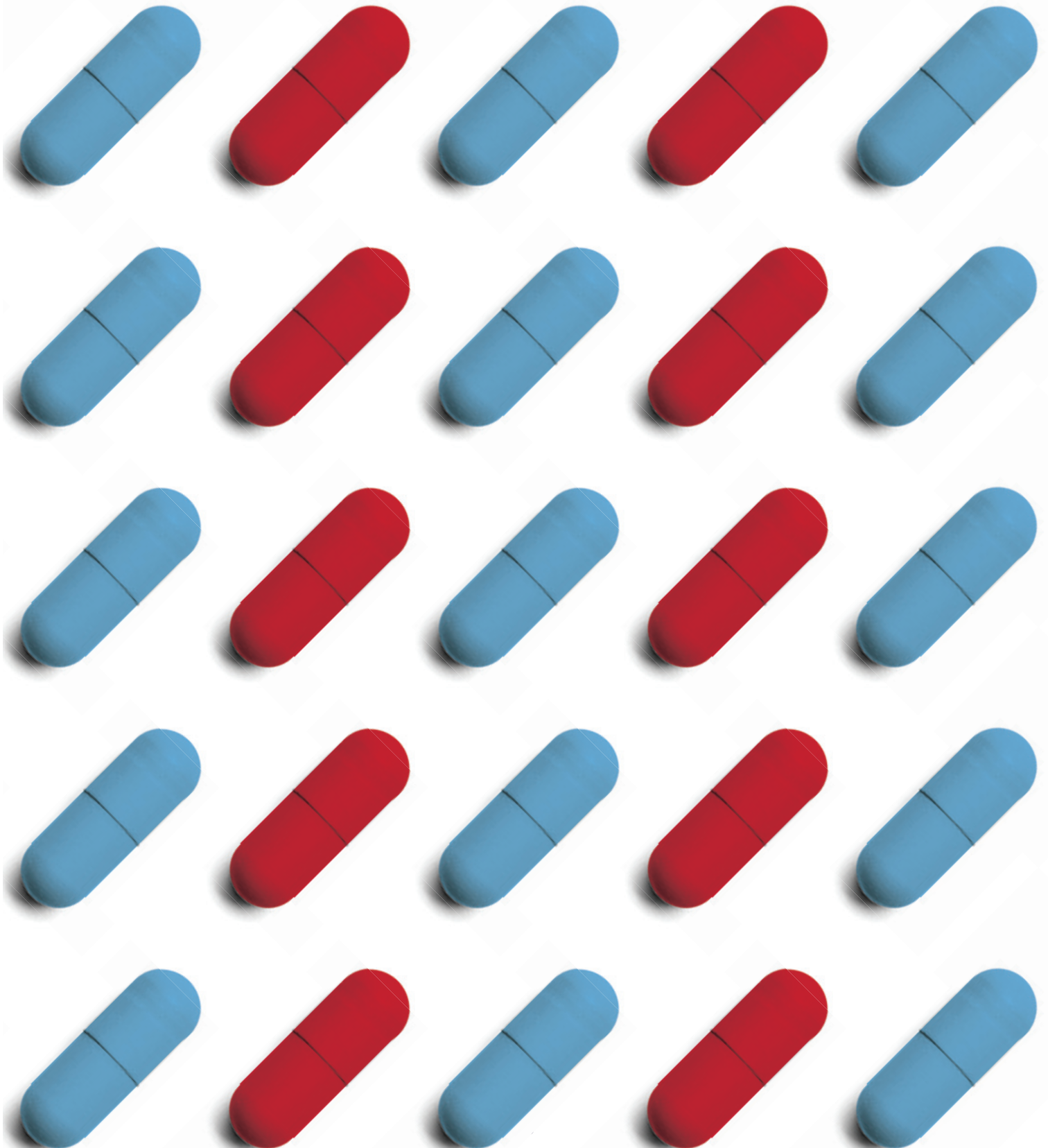


Attitudes towards opioids among patients prescribed medication in Victoria.



Acknowledgements

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Attitudes towards opioids among patients prescribed medication in Victoria

MOVE muscle, bone & joint health has undertaken an exploratory qualitative study for the Victorian Government examining consumer attitudes to opioid medications to inform future policy on pain management and prescription medications for people with chronic pain.

Key findings

- People have a love/hate relationship with pain medications.
- Many people experiencing pain have a range of chronic health conditions, including mental health issues.
- Medications are seen as a necessary evil to allow people living with pain to get on with their lives.
- Many people taking opioids for pain management feel that they are treated like drug addicts, and they resent it.
- Most people believe they have received good information about their medications from their doctors, with some exceptions.
- Many people look up their medications and other options on the Internet, although most struggle to find relevant, appropriate and accurate information.
- Pain medications are not a complete pain management solution for people living with pain; many participants see non-pharmaceutical techniques as part of a suite of pain management strategies.
- There is a clear impression that alternative pain management techniques are less likely to work the more severe the pain.
- There is a very wide variation in people's attitudes to and knowledge of nonpharmaceutical pain management techniques.
- Most people are willing to consider trying non-pharmaceutical techniques, but without much expectation that these techniques will eliminate the need for pain medications.
- Nearly all respondents believed that they will be using pain medications for a very long time or the rest of their lives, and they are worried about what that will mean for their health and their ability to participate in the community.

Context for the study

In Australia the prevalence of chronic non-cancer pain (defined as pain for a period of three months or more in the last six months) is 17 per cent in men and 20 per cent in women, with chronic lower back pain and osteoarthritis being the most common causes.¹

Opioid therapy is a common treatment for chronic pain. In 2013, there were 241 preparations for 12 opioid analgesics available for prescribing in Australia. Morphine (87 preparations), tramadol (48 preparations), fentanyl (43 preparations) and oxycodone (37 preparations) have the highest number of preparations. Eight opioids are currently subsidised by the Pharmaceutical Benefit Scheme (PBS): buprenorphine, codeine, fentanyl, hydromorphone, methadone, morphine, oxycodone and tramadol.²

Although short-term opioid therapy has been shown to be effective, there is limited evidence of the long-term benefits of opioid use for any indication.³ Overall it is estimated that 40–70 percent of people with chronic pain do not achieve adequate pain relief.¹ Furthermore, long-term opioid therapy is also associated with serious adverse effects such as depression, anxiety,⁴ misuse and addiction.⁵ The risk of sudden death due to opioids can also be amplified in the context of concurrent benzodiazepine and/or alcohol (mis)use.⁶ Other adverse effects also include constipation, sedation or dizziness, which can also significantly impact of people's ability to function.⁹

Data from the MOVE muscle, bone & joint health Help Line show that approximately a quarter of callers are concerned about their medication.⁷ Further, a consumer survey in 2013 showed that pain management was a significant concern for 45 per cent of respondents.⁸

A recent systematic scoping review of consumer needs for health information, health services and other non-medical services showed that many patients are concerned about pain management in the context of muscle, bone and joint conditions.⁹

Many people do not have a strong understanding of their medicines and want information about alternatives available to manage their pain.^{10 11 12} In addition, many people do not take all of their medicines as prescribed,¹³ with consumers often reporting confusion about their pill regimes due to a range of factors.¹⁴

The harms from prescription drug misuse and abuse are significant. In 2015, there were 330 Victorian drug overdose deaths involving pharmaceutical medicines, higher than the number of overdose deaths involving illicit drugs (217), and higher than the road toll (252).¹⁵

Commonwealth data shows that analgesics (including opioid analgesics) cost the Pharmaceutical Benefits Scheme (PBS) \$589 million in 2014-15, with taxpayers contributing \$473 million of this amount.¹ There was a nine per cent increase over the previous financial year.

Over the past 30 years there has been a substantial increase in the prescription of pain medications in Australia; with a 400 per cent increase over the last decade.^{16 17} Australia currently ranks 8th in the world for opioid consumption, despite limited evidence for the longterm efficacy of opioid medications. Possible explanations for this increase may include:

- the expansion of the PBS listing of opioids to include non-cancer pain
- patient and prescriber preferences for specific opioids
- the use of first line opioid therapy instead of the therapeutic guideline recommendation of second line use (i.e. once all non-narcotic analgesics have been exhausted)
- increasing ageing population
- increase in the prevalence of pain, and/or reduced availability of illicit drugs.²

The personal, economic and community costs and benefits of pain medications are substantial. The harms from prescription drug misuse and abuse can be catastrophic.

The benefits of good pain management are also significant, with many thousands of Victorians able to work, go to school, and participate in the community rather than being functionally disabled by pain. Good pain management techniques can be transformative for quality of life. The Victorian Government has introduced a range of initiatives to promote the safe and effective use of prescription medicines. Most recently, the 2016-17 State Budget included a commitment to implement real-time prescription monitoring in Victoria, backed by funding of \$29.5 million. This initiative will involve the roll out of a software system to over 1,900 medical clinics, 1,300 pharmacies and 200 hospitals throughout Victoria, as well as training and support packages for doctors and pharmacists.¹⁸

To ensure the best possible public policy outcome, the roll out of real-time prescription monitoring must be cognisant of the habits, perceptions and beliefs of consumers who use pain medications. This study was commissioned to begin the process of understanding consumers' views of opioid prescription to inform the government's design and roll out of thereal-time prescription monitoring system.

¹ Oxycodone (\$80m), Buprenorphine (\$71m), Oxycodone + Naloxone (\$57m), Fentanyl (\$38m) and Tramadol (\$24m) are among the highest cost prescribed medications in the analgesics category. Data from <https://www.pbs.gov.au/info/browse/statistics>, accessed June 2016

Method

This was a small exploratory study which aimed to recruit a convenient sample of 36 people who had been using opioid painkillers for three months or more.

Participants

This study specifically recruited participants meeting all of the following criteria:

- aged 18 years or over
- residing in the state of Victoria, and
- prescription of at least one opioid medication for a period of three months or more.

Opioid medications could include any of the following: Panadeine Forte, Comfarol, Codeine Phosphate, Zaldiar, Mersyndol, Tramal, Tramahexal, Paradex, Di-Gesic, Kapanol, MS Contin, MS Mono and OxyContin.

This study sourced participants using targeted muscle, bone and joint health lists such as MOVE muscle, bone & joint health's members and peer support group contacts. Patients were recruited through Internet advertising and social media, with a number of direct approaches such as contacting people directly to ensure that there was a representative cross section of participants

Semi structured interviews

We used a semi structured, interview method to explore the participant's responses on key issues relating to their beliefs and attitudes towards opioid medications. Interviews were 20- 30 minutes in duration with the aim of collecting both demographic and qualitative data, including:

- demographic data such as age, gender, residence (in particular, rural or urban areas)
- use of opioid medications and duration of use, and
- qualitative data such as whether they perceived their medication to be effective with regards to pain relief; whether they were happy taking it long term and whether they had discussed how they felt with their health professional.

We also explored where they sourced information regarding their medication and also whether they were open to using non-pharmaceutical therapies for their pain and tapering their dose of their current opioid medication.

The interviews were guided by a consistent set of queries designed to elicit responses regarding patients' experience in taking opioid medication, and how these people source information about the drugs they are taking.

Analysis

Interviews were recorded and transcribed. Analysis was ongoing throughout the fieldwork to allow emergent themes to be fed back into the data collection. A second researcher read all transcripts and assisted in corroborating and identifying additional themes. Common themes were then pooled and analysed.

Detailed results

Demographic and medications

For this study we interviewed 27 eligible participants (20 females and seven males) who were prescribed opioid analgesics for pain relief.

Respondents generally reported that their pain was associated with one or more musculoskeletal condition(s) and/or due to neuropathic pain, and in one respondent pyoderma gangrenosum due to Crohn's disease and multiple surgeries of the intestine. Participants varied in age from 25 to 77, with a good spread of age groups. Seventeen respondents described where they lived as urban, five respondents as rural and four respondents were on the outskirts of major towns. This distribution is not significantly different to the population distribution in Victoria.

Not all respondents stated what disease they had. Those that did had the following conditions: rheumatoid arthritis, fibromyalgia, osteoarthritis, psoriatic arthritis, lupus, Perthes disease, fractures due to osteoporosis, ankylosing spondylitis, chronic back pain, chronic neck pain, fasciitis, arthritis, reactive arthritis, sciatica, cyst, Sjogren's syndrome, neuralgia, bursitis, systemic lupus erythematosus, spinal stenosis. Two respondents had undiagnosed aches and pains. Most respondents, in particular those aged over 65 years, had comorbidities.

The majority of respondents were taking a combination of pain medication for pain relief, as well as other medication for co-morbidities. The most commonly prescribed opioid pain medication reported amongst this group was Endone (7 consumers were prescribed this medication), Panadeine Forte (7), Norspan Transdermal Patch (6), OxyContin (5), Tramadol SR (5), Kapanol (3), Targin (3), OxyNorm (3), Palexia (2), Ordine (1), Codeine Phosphate (1), Comfarol Forte (1) and Di-Gesic (1). Two respondents had been administered pethidine injections in the past when the pain was extremely bad.

In addition to opioid medications, consumers also reported being prescribed the following non-opiates: Ramipril, Nurofen, Meloxicam, Panadol Osteo, Panadol, Lyrica, Sulfasalazine, Enderp, Gabapentin, Asprin, Celebrex, Prednisolone, Allegron, Nortriptyline, Cortisone, Peroxin, Infliximab, Enbrel and Ketamine.

Effectiveness

The perceived effectiveness of pain medication varied from person to person interviewed. For the large majority of consumers the opioid analgesics "almost" worked. All of the consumers interviewed were at a dose that allowed them to function, but they all had unresolved pain of varying degrees for which they used a number of different pain management strategies to keep it under control. There did not appear to be any correlation between age, gender, place of residence or employment status with expectation of pain relief.

“Basically I’m aware my pain isn’t going to disappear in a hole. What I’m hoping is [to] keep the pain to the lowest level possible where I can manage it.” – Male, 60s

“Well, ideally with pain relievers you would ... want to have zero pain while you’re taking them. While I don’t have zero pain while I’m taking it, my pain is significantly reduced. So it’s not 100%, but it’s 90 to 95% of my expectation.” – Female, 30s

Whilst consumers did not like taking pain medication, they believed the medications significantly improved their lives and they were grateful. Depending on their condition and levels of unresolved pain, their pain medication allowed them to function, remain mobile, care for their children and continue working which were all extremely important for how the participant felt about themselves and their general outlook on life.

“Yeah, I work full time as a senior lawyer for a global organisation, so it is effective. I travel a lot for work. I work full-time, I’ve got [X] young children, so it’s pretty essential.” - Female, 30s

From the interviews conducted there seem to be two common ways of administering pain relief. Respondents tended to either take a slow release tablet or patch continuously and have Endone and Panadeine Forte prescriptions for breakthrough pain. Alternatively, respondents would take non-opioids and if they found them to be ineffective that particular day they would try increasingly stronger pain killers like Panadeine Forte followed by Targin or Di-Gesic until they got relief.

Respondents seemed to be in agreement that the aim was to bring the pain down to a manageable level before it spiked because once they experienced a flare it was difficult to bring it back down.

An emergent theme regarding effectiveness was that opioid needs changed over time depending on what was happening in the respondent’s private lives, for example the amount of stress they were under mentally and physically, the time of year and the weather. They discussed that some weeks were better than others and that during these times they took less pain medication, but that there were times when they needed more and they were frustrated that the current surveillance system do not allow for these differences.

Communication

The majority of respondents had a healthcare team that was composed of a number of different specialists including two or more of the following: general practitioner, rheumatologist, pain specialist (who were often also anaesthetists), gastroenterologist, neurologist, renal physician, psychologist, surgeons and cardiologists. Many people also reported consulting allied health practitioners such as physiotherapists, podiatrists and psychologists as part of their care team.

Generally speaking there seemed to be two different types of patients, those who were apprehensive about taking an opioid analgesic and who received encouragement from their doctor or their surgeon to try it and those who were desperate and willing to try anything. In the case of the former, patients discussed their concerns at length with their GP who answered any questions they may have had about it.

The information was not always accurate. In one particular instance a consumer reported being prescribed Palexia. She was not told that Palexia was an opioid because, in her view, the doctor knew she was so strongly against taking them.

All of the respondents had to return to their GPs on a regular basis for repeat scripts, either for pain medications or other medications. It was during these visits to the doctor that the patients would discuss how they were going with their medication. The majority of respondents had long standing relationships with their doctors and felt comfortable discussing any issues that

may arise, such as for example drug implications during pregnancy or changing the medication once it was no longer effective.

As indicated earlier the majority of respondents, with a few exceptions, were already at the minimum level of pain relief. That is, the dosage they were on reduced their pain to a score of two or three out of ten. They lived with a level of pain that still allowed them to function and they utilised other pain management techniques to help them deal with the unresolved pain.

Generally speaking once a satisfactory combination of opioid analgesics and complementary treatments was established both the respondents and their doctors were apprehensive about meddling with it in terms of reducing the dosage further. However patients were open to discussions about reducing the dosage.

One common theme that did emerge was that those patients whose pain medication was being reduced by their doctors often felt they had no other effective means of coping with the pain. As one respondent stated:

“You feel like you’re just not being listened to; they don’t understand the amount of pain that you’re in and they say, ‘Well just go with this for a couple of weeks and see how you go,’ but they don’t seem to understand that a couple of weeks of going along with extreme pain is a lifetime.” – Male, 40s

Only a few of the respondents interviewed had been to a pain clinic where they had instruction in other types of pain management techniques.

Pain Management

No respondents described opioid pain medication as sufficient for pain relief in itself.

Respondents complemented their pain medication in a variety of ways including consulting range of health practitioners, mindfulness, exercises and supplements, as well as different diets, generally eating healthily and trying to remain as active as possible and keep their minds busy.² One respondent noted that his guide dog was great pain therapy.

Depression was frequently mentioned as a co-morbidity.³ The focus of the interviews was not on mental health issues but those who felt strongly about it spoke about how they feared succumbing to depression. They were afraid that if they became depressed they would not be able to handle their pain any longer.

Some felt resigned to mental health issues whilst others did everything they could to avoid sinking into depression.

² Respondents reported: mindfulness or visualisation, breathing techniques, heat packs, cold packs, Bowen therapy, Alexander technique, acupuncture, aromatherapy, eastern medicine, iatromathematics, physiotherapy, chiropractic, stretching, yoga, remedial massage, occupational therapists, exercise like water aerobics, Pilates, tai chi, hydroponics, riding an electronic bike, walking, swimming, osteopathy, hot spa, cognitive behavior therapy, dry needling, naturopathy, hypnotherapy, tapping, vibrating cushions, resting when needed, music, colour therapy, listening to audio books, computer games, watching or listening to comedy, seeing a psychologist when feeling overwhelmed, neck brace or hand braces and supplements such as aloe vera oil tablets, fish oil tablets, tumeric and herbal remedies.

³ The Australian Institute of Health and Welfare (2016) reports that three in ten people living with back pain are living with mental health issues – twice the rate of the general population. AIHW 2016, Back problems, associated comorbidities and risk factors, available at <http://www.aihw.gov.au/back-problems/associated-comorbidities-and-risk-factors/>, accessed 18 June 2016.

The effects chronic pain had on mental health was discussed most frequently in relation to alternative and complementary therapies. Respondents spoke about how these techniques were also useful in supporting their mental wellbeing. Practices such as yoga and Pilates made the respondents feel in control over their illness and this gave them a sense of empowerment. Mindfulness and breathing techniques allowed them to relax and become more accepting of their situation.

“Pilates is ... the most important thing to me... just keeping my body moving and it really helps me stay positive that I’m actually doing something to maintain my body and I’ve got a bit of control over how things go.” - Female, 40s

Complementary and alternative therapies were seen as an adjunct to pain medication. Respondents felt that these techniques helped them accept their pain and manage it. They also thought that they were effective at helping them stay on a stable dose of their pain medication. Techniques such as mindfulness and visualisation were difficult to master and those respondents who had been practicing for longer were able to get more out of them. Depending on the condition, exercise appears to be the most effective form of pain management and therapy. People who successfully managed to reduce their dose of pain medication or come completely off it were engaging in as much physical activity as they could within their limits.

Respondents did not think it plausible that these therapies could replace pain medication. They pointed out it was impossible to sit down comfortably and do mindfulness if you were in pain that was a seven or eight out of ten. Sometimes pain medication was necessary for them to engage in physical activity such as walking and Pilates.

Respondents described their pain management routine as a complete package that is composed of a combination of both pain medication and non-pharmaceutical therapies that were practiced when their pain levels were at five or four or lower. These therapies were just not strong enough for severe pain.

“Pretty effective but you’ve got to get used to the fact it’s a subtle energy manipulator, it’s not a sledgehammer like a drug is, but there are times when only the sledgehammer is appropriate.” – Female, 50s

Another participant with osteoarthritis in both knees who reduced her dosage, stated:

“It’s only because I’ve been doing the exercises that I’ve been doing [that she was able to come off the Targin]... and then it took probably almost 12 months before I really noticed that it didn’t need to use a walking stick all the time. I know I won’t ever be cured of osteoarthritis but I know I am in a better position to be able to manage it...” – Female, 60s

Depending their condition, most respondents were willing to try “anything and everything” that may help with the pain. Few patients reported hearing about non-pharmaceutical pain management techniques from their doctors. When it was suggested by a doctor it was usually from a pain specialist or learned at a pain management clinic, although for the most part the respondents had already been engaged in these therapies prior to being prescribed opioid pain medication.

Relationship with pain medication

Most of the participants interviewed had a love/hate relationship with their medication. Whilst they were grateful for it on the one hand they were also aware that it was not good for them. However, as they saw it they did not have a choice as long as they were in chronic pain. As indicated earlier many of the respondents were apprehensive about taking it at first. For example:

“I thought of junkies and I didn’t want to be one of those people” – Female, 40s

“Initially I was reluctant to try it. My GP had suggested it to me and I was reluctant to take it just because of the kind of medication it is and the bad connotation that people have of these kind of medications ... Since taking it, I’m happy taking it because of the positive impact that it has on my life.” – Female, 30s

Those who experienced side-effects found it particularly difficult balancing maximum pain relief with side-effects such as nausea and lack of concentration which made keeping a job difficult to do. There was a general feeling of resignation, that if the respondent wanted to have some sort of quality of life they would have to keep taking pain medication.

“I am so grateful there’s something there that can do at least what it does because I would have killed myself otherwise.” – Female, 50s

Almost all of the consumers we spoke to indicated that they would continue to keep taking them in the future for as long as they need to. Three just had or were in the process of coming off their medication. Many were expecting to take opioid medications for the rest of their lives.

Where consumers sourced information

A number of different themes emerged throughout the course of the interviews in regards to consumer’s information needs.

Consumers gathered information about the pain medication they were taking from a variety of different sources. GPs and pain specialists were usually the first point of call and the most frequently cited source of information.

The internet was the second most frequently cited source of information. This included Google searches as well as visiting websites such as MediGuard, Medscape, National Prescribing Services’ MedicineWise and Wikipedia.

Participants also visited Australian and overseas consumer forums such as Drugs.com, Facebook support groups, arthritis community forums offered by various consumer organisations around Australia such as MOVE muscle, bone & joint health, as well as selfhelp groups.

Other sources of information included pharmacists, information sheets that came with their medication, newsletters and information developed by consumer organisations such as MOVE muscle, bone & joint health, Arthritis NSW, Arthritis Australia, as well as overseas based arthritis and disease specific organisations such as the Ankylosing Spondylitis Association.

Other patients used news and magazines as a source of information, as well as family and friends with medical knowledge. Peer reviewed journal articles, medical books and professional databases were also cited. One respondent was a health professional and she sourced information from clinical on-line portals and forums.

“One thing that I do find difficult about finding information is quite often it’s written for a doctor or for a pharmacist as opposed to written for a consumer... and that’s where forums, I think, are much more important than say a site like Wikipedia or even the information sheets in the products.” – Male, 30s

While sourcing information was not a problem, the consumers we spoke to differed in their opinion about how easy it was to find information that was credible and useful. Consumers expected their doctors to be knowledgeable about the pain medication they were being prescribed. Consumers who described their doctors as very good were more likely to be satisfied with the information their doctor gave them about their medication.

Pharmacists were also considered a reputable source of information although only a small number of consumers utilised them for information.

Information sourced from the internet was described as being “a bit of a mish-mash”. Consumers felt that there was no lack of information about the pain medication they were on, but it was not necessarily useful to them. One of the biggest issues consumers cited about the information they sourced on the internet was that it was too technical and that it therefore did not offer them much more understanding than the information sheets that came with the pain medication they were prescribed. Another issue was simply the large amount of information, much of it conflicting, that consumers had difficulty navigating through.

“Oh yes, it’s all over the internet everywhere... everyone’s got information about that, but that’s what I mean, that some of the information is confusing.” – Male, 40s

The conflicting nature of the information available was not only reserved for the internet, and a few consumers also cited differences of opinion amongst doctors. As one respondent explained:

“I usually try to sort of look things up online but it’s just such a pitfall there’s too many, too much misinformation... So once I sort of did do a Google search and found that there was just no right or wrong answer, there was just too much speculation I sort of put that aside” – Male, 30s

Another consumer stated:

“I can get all the information in the world but it’s all conflicting.” – Male, 40s

The majority of consumers felt the need to verify the information they found on the internet with their doctors and friends and family who worked in the medical field, or they would raise their concerns about the information they sourced within self-help groups and community and online drug forums.

What information consumers sourced

Consumers wanted to know how their particular pain medication fit into the hierarchy of opioid analgesics. Consumers discussed how they were “grasping in the dark” for pain medication not knowing what else is out there.

Consumers wanted to know what pain medication was best to take long-term. They sought out information about their condition, they wanted to know the long-term and short-term side effects of the pain medication they have been prescribed and whether there were any alternatives to the medication they were taking. This was where forums were particularly useful to consumers because people were discussing how the pain medications affected them personally and how this affected their day to day lives.

They were also a source of information about what is trending and what the current practices are. Consumers could discuss how to get the most out of their pain medication without having to escalate in dosage (for example, potentiators of opiates). They provided a platform:

“Where you talk to other people about what they have tried and what they have found and what they have learnt.” – Female, 50s

Peer experience was particularly valuable because as another participant noted:

“You can list a whole heap of side effects, but the one thing that you never really know until you start taking a medication is how it actually affects you practically on a day-to-day basis...

“...you can actually make your condition worse when you are on pain medication because you don’t actually feel that pain so you can push your body and end up doing harm to yourself which is something that I don’t think is spoken about very often.” – Male, 30s

One participant had wanted to know what the implications were in pregnancy and what pain medication was best during this time. Consumers also wanted to know how to wean themselves off the pain medication they were on.

Consumers were frustrated about the lack of Australian-specific information and information sources. There was also a lack of information about side-effects such as addiction and physical dependence in terms of what this actually meant. Participants who experienced these side-effects spoke about how they were unprepared for the physical and mental withdrawals they had to go through. They wanted to know what pain medication was least harmful to take in the long-term.

Participants also wanted more information about their condition. They wanted to know what the future was with their condition. They required information that would tell them about how to adjust their lives to live with their illness and how to best manage their pain using alternative methods.

Concerns about pain medications

All of the consumers interviewed expressed that they had concerns about taking opioids. The most commonly cited concerns were tolerance and organ damage. Tolerance and damage to the internal organs was concerning because of the chronic nature of the consumer’s illness and the general consensus that they would have to be on some sort of pain medication for the rest of their lives. Monitoring liver and kidney function was routine for a few of the consumers we interviewed.

Participants spoke about their anxieties about the future and whether or not their pain medication would continue to be effective. Unresolved pain was an issue and consumers did note that they would prefer to live without pain. However, they were fearful of escalating their dose because of what this might mean for the effectiveness of their pain medication in the future. Participants also worried what would happen if they had to have an operation and how they would cope with post-operative pain.

“I guess building up a tolerance to it and then like you know if you go and have an operation or something like that then you need you know more than what a normal person would ... you know what will I be needing if I’m taking this dose now, what will I need when I’m 60 or something like that if it’s still a problem?” – Female, 20s

“My biggest fear, as I mentioned, is that it will get to a stage where it’s not effective and the pain gets to a level where I can’t function in my daily activities.” – Male, 60s

Other concerns cited were drug interactions. One participant noted that she carried around with her a letter in case of an accident that would inform whoever was treating her of the different medications she was on in order to avoid life-threatening interactions.

Overall, the majority of consumers interviewed did not believe they were at risk of addiction. They pointed out that they always took the drugs as prescribed. The small number of consumers for whom it was a concern were those who had noticed that they were physically dependent on their pain medication or those consumers who have had to wean themselves off opioid pain medication in the past and found it extremely difficult. Apart from those who felt themselves to be or to have been physically dependent, others did not mention this as a concern.

“I was worried – I was so worried at first about getting addicted. And the doctor, you know, kept telling me that, “Look, you don’t get addicted if you’re taking it to kill pain,” you know?” – Female, 60s

Consumers spoke about how they did not want to be on medication but ultimately they felt like they had no choice. There was a general sense of resignation.

“So you just wonder what your body is doing, you know, with all these things, and I do get concerned about it. But what can I do darl’, because I know I couldn’t live with the pain without being on something, you know, life would just be absolutely, well, it wouldn’t be worth living.” – Female, 70s

“I would rather not take anything. It took me years and years to accept that I had to take medicine of this type, or that type, or whatever, but I’m just resigned to it now. I need it, I have to have it, I do everything else in my power to stay well and what have you and that’s just part of my life.” – Female, 50s

“Most people don’t want to take medications for a long period of time, but by the same token I don’t really have any choice; if I don’t take Targin or something similar to it, I can’t live my life.” – Female, 30s “I was very reserved before I went on to opioid-based painkillers and even now taking them I take them because I need to take them, but I actually don’t want to be taking them.” – Male, 30s

Side effects

Consumers were aware of potential side-effects caused by their pain medication. However they were often unprepared for how a side-effect actually manifested itself and how this would then affect them in their everyday life in terms of family relationships, their work and their mental health and wellbeing.

Just over half of the consumers interviewed experienced side-effects from their pain medication. The most common side-effects raised were constipation and feeling drowsy. Other side-effects mentioned were excessive sleepiness or finding it difficult to stay awake nightmares, hallucinations, fogginess, upset stomach, nausea, recall, forgetfulness, weakening of the bladder and dry mouth. One consumer described himself as being:

“basically stoned ... I’ve been on occasion unable to drive ... because it just affected me so much mentally, there are times where I actually haven’t been able to think and process my situation that well.” – Male, 30s

One consumer noted that contrary to the warning label printed on her medication, the medication actually keeps her awake and she has to lower the prescribed evening dose in

order to sleep. One consumer, who had been on OxyContin for nine years, stated that his liver was beginning to show signs of damage and he was suffering from physical dependence symptoms like itchy skin and what he, and two others described as “skin crawling”.

Tolerance was an issue. The majority of consumers interviewed had over the course of their treatment escalated in dosage. A common theme was of experiencing a flare up and finding that the previous drug combination was no longer effective or undergoing surgery and being placed on a higher dosage or a stronger opioid analgesics and not being able to manage the pain thereafter when the dose was reduced.

For some consumers it was simply becoming increasingly more de-sensitised to the drug over a period of time. In one extreme case one respondent felt that the morphine she was taking (70ml in the morning and 70ml at night) for arthritic pain was no longer effective. She had been constantly on it for more than 20 years. For patients like her, Ketamine injections were occasionally given. The effectiveness of these was mixed. It seemed to work really well for some people and for others it did not have an effect after the first time. Others reported a negative reaction to Ketamine.

Generally speaking consumers did not mind being on the pain medication they were on as long as their dose did not increase.

“And I’m always careful. I’m so careful. You know, the sort of overdoses just frightens the daylights out of me. So I’m very, very careful how I take them and what I take with them.” – Female, 60s

There also did not appear to be any pattern between what made it difficult for some consumers to wean themselves off the pain medication they were on, and for others to suffer physical withdrawals.

“It was like things crawling inside me, I was really restless, really, really restless and nauseous, yeah, and I remember just curling up on the couch just feeling dreadful, thinking I’m never, never taking an opioid ever again and well, here I am.” [Details suppressed]

For others there were no mental or physical problems scaling down.

Because many of the consumers interviewed had other co-morbidities and were often on a number of different pain medications (including anti-inflammatory medications), it was hard for them to conclusively determine whether or not they were experiencing side-effects from the opioid medications, other medications or generally growing older.

As indicated earlier consumers had weighed up the costs and benefits of taking opioid medications and the general consensus was that “the alternative is – there isn’t an alternative.”

Other comments

An emergent theme throughout the interviews was the significant degree of judgement consumers felt from doctors, society and the Government about opioid use. They argued that this was hypocritical considering that other pain relief drugs also carried with them significant side-effects and that as science has progressed we have also learned that some things, like paracetamol for example, are not as effective as previously thought.

Consumers were tired of being judged, interrogated and lectured. They continually brought up the fact that they had been living with their conditions for years or decades and yet they were still forced to go to the doctor every month and to be under surveillance in terms of their dosage. They

felt that they were being treated like drug addicts by the medical establishment, society and the media. The media were described as sensationalising the issue of painkillers' dangers.

This perceived judgment affected some people more than others. Those who were affected described feeling ashamed and weak for having to resort to opioid analgesics for pain relief, while others were angry. As one respondent stated:

“... they treat everyone who takes these kind of medications as a drug addict; that's their perception, that's the way they make patients feel with their regulations. They don't see that's someone's mum, or someone's husband, or something like that; they don't see the actual people that take it.” – Female, 30s

This sort of societal attitude made it difficult for respondents to find doctors who were willing to work with them. Respondents brought up repeatedly how:

“the biggest problem is when you go to see a doctor... the way they look at you and treat you if they haven't known you for a long time... And if you to the hospital, or whatever, and you're just treated like you're some – trying to scam the system and get drugs out of them, or something like that.” – Male, 40s

Another emergent theme throughout the interviews was that of accessibility to services in rural areas. Rural respondents discussed accessibility issues and the costs related to travelling to services, and the lack of particular services such as tai chi and clinical Pilates.

“I haven't gone to a pain clinic because I had to travel [to the rural centre] – an hour travel, travel in, travel out – and to do that every day for – I think it was two weeks that ran for. I couldn't do that, it's too expensive anyway for me to do it.” – Male, 40s

Discussion

Living with pain is difficult, and it is clear from these interviews that many people living with pain struggle with day-to-day tasks. People want to work, learn or participate in the community, and their pain creates difficulty in participation. Best possible pain management for these people, their family and their carers is vital to ensure that people living with pain are able to get on with their lives.

Every respondent felt that their pain medication was necessary for them, albeit in most cases, a necessary evil that was not sufficient to deal with their pain. Barriers to accessing pain medications need to be carefully thought out in this context. People living with chronic pain will have good days and bad days, and difficulties on a bad day may mean that people may be unable to access their medications.

Yet it is because of these bad days that a real-time prescription monitoring system could be of great assistance to people living with chronic pain. A sympathetic and informed provider using the system will be able to ensure that people access the pain relief they need, help avoid medication errors, and be a tool to identify people who may benefit from being given more information and choices about their pain management.

Who first prescribes pain medications

One unanticipated aspect of this study was the variance on where people first received pain medications. This question was not asked directly, but a number of responses addressed the issue.

Regularly, respondents reported first receiving an opioid prescription from someone other than their regular doctor. In one case, Endone was supplied by a friend, and the respondent then sought a doctor's prescription. A number of other respondents were supplied painkillers for the first time following a hospital admission, with subsequent prescriptions from medical practitioners in the community.

Respondents described receiving prescriptions from general practitioners, a range of specialists, and occasionally, a hospital doctor. The study did not reveal any respondent deliberately seeking painkillers from a range of providers inappropriately. While a number of those interviewed highlighted that their doctors were in regular contact with each other, there are risks with multiple prescribers servicing the same patient. Unless the communication and feedback is very clear, the potential for errors is significant.

Where patients get information from

The two most common responses were that patients got their information from their general practitioner and other doctors, and the internet (both information pages and peer-to-peer forums). Friends who were also living with chronic pain or had a medical background were also mentioned as a source of information.

Generally speaking where information was gathered from doctors or pharmacists, respondents had all of their questions about the medication they were taking answered.

However, those who used the internet to gather information encountered difficulties sourcing useful information from trusted and credible sites. Participants repeatedly stated the internet provided a plethora of information that was inaccessible because it was not written for consumers and unless they had experience in medical research they found it difficult to interpret what is good from bad.

Because of the lack of accessible information on medical sites respondents turned to forums for information where they could participate in conversations with other patients and learn from their experiences. Another unexpected finding was the need to access overseas forums, particularly US forums where those engaging in the discussion appeared to have more knowledge and experience compared to Australian patients prescribed opioid pain medication.

The interview responses highlight the need for a trusted knowledge hub of information specifically tailored for consumers, where relevant information has been synthesised and written in plain language.

The knowledge hub should include information about the following:

- specific conditions
- pain management strategies
- opioid pain medications – how they work, side-effects and how they manifest themselves in real life, how to wean off, possible drug interactions, case-studies of other people's experiences
- other pain medications – such as steroids and immune modulators
- other pain therapies and treatments, and
- how different pain medications fit together in a hierarchy.

Education of health care professionals

Doctors were rarely the source of information for alternative and complementary treatments such as acupuncture and remedial massage. Overwhelmingly respondents learned pain management strategies through pain clinics for which there were long waiting lists, through friends or from having previously practised them. More needs to be done to educate health professionals about possible complementary and alternative therapies for chronic pain and to make these more readily accessible for people with chronic pain conditions.

Both of these findings highlight the importance of organisations connecting patients and health professionals to information resources and peer support.

Pain management planning

There was a general lack of mutual planning for the future between general practitioners and patients. Exceptions include the few patients who intended to come off their opioid pain medication and had a plan to do so, and those who attended pain clinics and received structured instruction about how to manage their pain.

The vast majority of patients had no long-term goal in terms of pain management and resigned themselves to continue taking opioid pain medication for the rest of their lives.

This lack of long-term goal setting was observed even when patients were aware of increasing desensitisation to opioids, or they knew their medications diminished in effectiveness over time.

There appears to be the need for an holistic and systematic approach to chronic pain management that involves a mutually agreed plan between general practitioner and patient that factors these important issues into account. It is not sufficient, and rarely clinically appropriate, to increase opioid dosage over time. A plan needs to be put into place, and the patient needs support throughout their treatment journey in order to minimise the escalation in dosage.

A monitoring system could assist to prompt and then help develop a pain management plan between GP and patient where the expectations of both could be addressed and an achievable goal for each individual patient determined. If the real-time prescription monitoring system is to be used for this purpose, plans need to be individualized; consumers need some measure of flexibility in the way their pain medications are prescribed, particularly during severe pain episodes which at times cannot be avoided.

Stigmatisation of people on pain medication

Our findings indicate that patients feel ostracised and made to feel ashamed for taking opioid pain medications. Patients report reprobation from doctors, pharmacists, the general public and even their own friends and family. This stigma associated with opioid pain medication may have a negative impact on their mental health and wellbeing.

The stigma also appears to form a barrier against open and honest discussions about pain and ways to manage it. Ways to mitigate this issue need to be developed. More education is needed about chronic pain and opioid pain medication. Patients need to be encouraged to share their experiences openly, rather than suffering in silence because of shame and guilt.

Accessibility

Respondents reported a number of accessibility issues affecting their pain management, including physical access, timely access and cost.

As expected, people living in rural and remote areas reported physical access issues, including the time to travel to a regional centre. Services that are plentiful in urban areas, such as Pilates and warm water exercise, are not readily available in some areas.

Timely access to services, such as specialist medical care, was described as an issue for some people.

The cost of some services, and the costs in travelling to services in rural areas, was also discussed by a number of participants. Many services that are proven to be effective in pain management are not available in the public health system, and patients' capacity to pay varies considerably.

Other considerations

Other issues that were raised in discussions with participants but not explored in depth include how people are using their pain medication, and how medical professionals are prescribing medications. Without more information it is not possible to conclude the clinical suitability of participants' individual pain management regimes, but there appears to be a prima facie variance with clinical guidelines in some instances. It is not clear from our investigations whether these variations are justified, and if they are not, whether it is an issue of prescribing or patient compliance.

Respondents regularly discussed the interactions of various types of medications for a number

of different conditions. Particularly where opioid analgesics are used in combination with other therapies, a real-time prescription monitoring system may need to consider polydrug interactions. If the public health objectives of reducing the amount of opioids prescribed is to be successful, then further investigation of the practicalities of tapering an opioid dose is needed. The practicalities may be different for patients that appear currently well managed, and patients who are not managing their pain well.

There are a number of non-pharmaceutical pain management techniques that are not well understood by patients or by providers. Promoting these alternatives will be challenging for people living with significant pain, and there will be ethical considerations that need to be addressed where people feel their mental and physical wellbeing relies on pain medications.

Limitations

Given the exploratory nature of this study there are a number limitations and caveats associated with the result. A key issue is that we did not achieve a sample of 36 eligible participants, however this is unlikely to impact the results. It would appear that we reached data saturation at a sample size of 20 with similar issues being consistently raised.

The pain of the respondents was predominantly due to musculoskeletal conditions, although many have co-morbidities. Patients were not expressly asked what contributes to their pain. As 58 per cent of opioid prescriptions in Australia are due to muscle, bone and joint conditions,⁴ it is unlikely that the sample skew towards musculoskeletal pain would compromise overall results.

Given the small sample size and the fact that patients were self selecting there may be issues relating to the general applicability of the results. For example our sample consisted of more women, mainly being prescribed strong opioids. The fact that the respondents were self-elected may indicate that these participants are healthier and better managed. Thus the sample may not reflect the experience of those whose pain is not adequately managed or abusing or misusing their medications. Due to the design, eligibility requirements and promotion vectors, the study is unlikely to have captured the views of people who deliberately misuse or abuse pain medications.

Our analysis of prescribing trajectories was based on the respondent's subjective account of their experience and may be subject to responder bias. The study was designed to ensure that participants were not identified even among the research staff; thus ensuring that participants were free to impart their experiences. Further, the questions were free form and not designed to illicit a specific response.

⁴ Harrison CM, Charles J, Henderson J, Britt H 2012 'Opioid prescribing in Australian general practice', MJA 196(6): 380-381

Conclusion

The rapid increase in opioid prescription and use across the community requires a response. Clinical guidelines and evidence shows we should be aiming to reduce opioid use.

A real-time prescription monitoring system can provide elements of that response. In addition to addressing the issues of doctor-shopping, misuse and abuse, a real-time prescription monitoring system could also be used to reduce legitimate patients' risk. It is also worth considering if the system could be built, or could develop to, a tool to help patients living with chronic pain better manage that pain by providing prompts for information and intervention.

Regardless of the eventual scope of the real-time prescription monitoring system, care must be taken to ensure that consumers living with chronic pain are not further stigmatised by the protocols and processes that are put in place. Resources and education for both patients and providers will be necessary to ensure that the risks of stigmatisation are limited.

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