

Title

Fact versus fiction: Bridging contrasting medicinal cannabis information needs

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MAIN TEXT

Public awareness and patient interest in accessing cannabis is high.(1, 2) In 2016, Australia enacted regulatory changes to permit an access pathway for medicinal cannabis through the Therapeutic

Goods Administration (TGA) Special Access Scheme.(1) A registered medical practitioner who wishes to prescribe medicinal cannabis for the treatment of appropriate patients outside of clinical trials may now do so following an application and approval process.

Meanwhile, in cancer care there remains mostly only low quality evidence to suggest medicinal cannabis may improve the cancer patient's experience of pain, wasting, vomiting, or nausea.(3-7) Multiple studies have recently commenced, with results still pending.(8-12) Clinicians are therefore working with a developing but limited evidence base,(13, 14) in addition to limited knowledge of the area, relatively new regulatory processes for prescription and access of medicinal cannabis products, and a growing patient interest in this medication.

In considering medicinal cannabis use in cancer and palliative care, clinicians must consider available evidence including: its strengths and limitations; patient and/or carers' requests; the place of medicinal cannabis alongside other treatment approaches; different ratios of active drug components for different indications; assessment of response and effects including adverse effects; and regulatory access pathways to prescription. Simultaneously patients and carers have heightened awareness of its availability and require accurate information to understand: the potential role of medicinal cannabis; the consent and safety implications of accessing medications outside of the TGA monitored processes; and practical aspects around storage, safety and driving.

The aim of this project was to develop and evaluate two informational resources for 1. cancer patients and their family to enhance understanding of the role of medicinal cannabis in cancer care; and 2. cancer clinicians to aid ready responses to patient and carer queries and referral pathways for specialist advice.

This study involved a three phase co-design approach (15, 16), with integrated input from consumers, clinicians, and policy/regulatory experts in the cancer care settings of three metropolitan teaching hospitals in Victoria, Australia. A Project Advisory Group was established to provide oversight, with membership including: three consumer partners; one senior medical advisor, Office of Medicinal Cannabis, Victorian Department of Health and Human Service; four Palliative Medicine physicians; two researchers; and one Integrated Cancer Service representative. Ethical approval was granted by the relevant institutional human research ethics committee (LNR/18/PMCC/122).

Phase 1. Exploratory qualitative approach: Focus groups and interviews were conducted with consumers and cancer clinicians to understand their information needs regarding medicinal cannabis. Approximately 100 consumers registered with the consumer engagement office of the hospital cancer services were invited by email to participate in a focus group. A researcher (SP) then contacted those who expressed interest to provide further study information and a time and date for the focus group. Cancer clinicians were invited at the cancer multidisciplinary meetings to attend a subsequent focus group. Participation was voluntary. All participants provided informed consent. Focus groups/interviews were audio recorded, transcribed verbatim and analysed deductively based upon key areas of questioning.(17)

Phase 2. Design and development of information resources: Two distinct informational resources for cancer patients/carers and clinicians were developed. These were informed by existing published literature, Australian Government TGA guidance documents, qualitative data from consumer and clinician focus groups and interviews (Phase 1), the project advisory group and relevant hospital health literacy and communications experts.

Phase 3. Evaluation of information resources: A different group of consecutive patients with cancer and their carers (n=18) attending two teaching hospitals' inpatient services were approached by a researcher (SP) and clinician (BL) and invited to participate in a face to face interview and survey to evaluate the information resource for patients/carers. Four declined to participate. A copy of the resource was left with each participant for review and a researcher (SP) returned after 30-60 minutes to conduct the interview and survey. Clinicians' feedback was sought through presentations at scheduled cancer multidisciplinary meetings. Minor adjustments to the resources were made accordingly.

Descriptive statistics were used to describe participant characteristics and summarise Phase 1 and Phase 3 findings.

Phase 1. A total of 14 consumers (64% female) who were former or current cancer patients participated in a focus group or interview. Most participants were either aged 18-25 years (43%) or 56 years and over (43%). While none had used medicinal cannabis, 57% had considered this, and one reported using self-sourced cannabis during their cancer experience.

Ten clinicians participated in two focus groups (50% male), over half with 20+ years of experience in their clinical discipline (n=6), majority were consultants in their clinical discipline (n=7), and most were oncologists (n=8). Six reported having had one or more patient request(s) for medicinal cannabis. None had prescribed medicinal cannabis at the time of the focus groups.

Key areas discussed by consumers and clinicians included: their existing understanding and knowledge of medicinal cannabis; information and content needs for resources; when and whom should raise the topic of medicinal cannabis; resource design format; and the dissemination process for sharing the developed resources.

Most consumers indicated that their existing understanding about medical cannabis were sourced from current affairs television programs, newspapers and the internet. They noted that there was very limited in-depth knowledge in the community about medicinal cannabis.

"There's a total lack of knowledge of what it is. They [general public] think they're [doctors] going to put it in a cigarette and give it to a child or something." – Consumer

Most consumers perceived medicinal cannabis to be a more 'natural' treatment option compared to other treatments or medications. Some consumers felt that information about medicinal cannabis had been withheld from the public:

"I really believe that pharmaceutical companies have always known about medicinal cannabis"
– Consumer

While other consumers perceived medicinal cannabis to be a treatment of cancer itself.

"There's types of cancer that marijuana kills outright. Like, you'd only have to digest it the once and bang." - Consumer

Clinicians reflected on the lack of research evidence supporting the use of this medication for pain and symptom management in patients with cancer. They therefore indicated that it should only be considered if proven agents were ineffective.

"We're talking about ... a family of drugs... There may well be some active ingredients in there...but we have absolutely no idea because it's not a drug, it's a whole bunch of things thrown in together" – Clinician

“It’s used when other things, when conventional treatments have been exhausted” -- Clinician

Regarding the content of an information resource(s), consumers and clinicians alike wanted clear, simple, concise information to be included.

“Information is power, but it’s to keep it simple, make it accessible” -- Consumer

“What we need to do is cut down the stories, the tales, the misinterpretations, to actually get... some information out that states ‘A, B, C, D, E and F’, it may not help you” -- Consumer

Clinicians also felt the content must include that: medicinal cannabis is not subsidized by the government; that it is not a cure for cancer; and that patients are unable to drive when using this medication. They highlighted that this content is the source of some dissonance between patients and clinicians and would assist in correcting some mis-information currently available around cannabis.

“It would be good to have ... as much information for patients as possible, considering this is a topic where patients come really distrusting us... they think we’re the gatekeepers who are refusing to give this miraculous drug ... there is too much us versus them” -- Clinician

Other clinicians wished to include details of dosage, administration, possible side effects, interactions with other drugs, and precautions. Associated costs and available clinical trials were noted by clinicians as useful but had limited constancy and were considered beyond the scope of an information resource.

Clinicians and consumers disagreed about when and by whom the topic of medicinal cannabis should be raised. Clinicians were clear that since this therapy is not underpinned by evidence, they would only consider medicinal cannabis as a last line medication option for patients. Consumers, by contrast, suggested that they would like doctors to raise this medication as an option just like other treatments:

“It should be brought up the way they [doctors] bring up the other treatment if this is now going to be an option” -- Consumer

Table 1 summarises the differing perspectives of clinicians and consumers regarding medicinal cannabis.

Table 1. Differing perspectives of clinicians and consumers regarding medicinal cannabis*	
Clinicians	Consumer Representatives
Is not a cure for cancer.	May be a cure for cancer.
Do not see it as their role to raise the topic/option of medicinal cannabis with patients.	Want doctors to bring up the topic/option of medicinal cannabis.
Evidence for the use of medicinal cannabis is weak and is to be considered only when all other conventional treatments are ineffective.	Belief that data supporting the use of medicinal cannabis was more mature; medicinal cannabis should be offered as a legitimate alternative similar to any other medication.
Aware some patients may perceive doctors as gatekeepers withholding information about medicinal cannabis.	Perceived that government, pharmaceutical companies and/or health professionals

	withhold information regarding the efficacy of medicinal cannabis.
Due to limited evidence medicinal cannabis is not subsidized by the government. More affordable medication alternatives with proven efficacy are available.	Medicinal cannabis should be included on the Pharmaceutical Benefits Scheme.
Patients are unable to drive when using medicinal cannabis.	Medicinal cannabis does not inhibit driving ability.

* These perspectives were common but not necessarily universally held by each group

Phase 2. Information from the data sources highlighted were brought together and discussed with the project advisory group to respond to the key informational needs articulated by consumers and clinicians (Box 1).

Box 1: Content covered in:

The Medicinal Cannabis Patient Information Resource

What is medicinal cannabis?; Is medicinal cannabis legal?; How can medicinal cannabis help you?; What does the research tell us?; Medicinal cannabis products; What are the side effects and risks?; Important information for you; Access to medicinal cannabis; Cost; and for more information.

The Medicinal Cannabis Clinician Information Resource

Use of medicinal cannabis; Medicinal cannabis products; Treatment and evidence; Dosing and administration; Treatment plan and monitoring; Side effects and interactions; Precautions and contraindications; Prescribing medicinal cannabis; Cost; Information regarding clinical trials; and links to further information and resources.

Phase 3. A total of 14 patients and carers (64% female, 57% aged > 56 years) with a range of cancer diagnoses participated in the evaluation of the Patient Information Resource. Five had sought information and 4 had previously considered medicinal cannabis, but none had been prescribed it. Two had used self-sourced cannabis for symptoms of pain, appetite, and/or stress. The majority agreed the resource was easy to understand (85%), that it answered their questions about medicinal cannabis (93%), and that they were likely or very likely to recommend it to others (100%).

Cancer clinician feedback regarding the patient information resource was broadly positive, with content, format and presentation considered accessible. Clinicians considered the resource useful to refer to when having discussions with patients and potentially time-saving.

A third of participants suggested that the 'impact of cannabis on cancer itself' be included in the resource. Clinicians suggested additional content highlight that there was, to date, no evidence that medicinal cannabis had an effect upon cancer itself, and also that it should not be used during pregnancy. These amendments were made.

The information resources are available online for all interested groups:

Patient Information Resource: https://www.petermac.org/sites/default/files/media-uploads/Medicinal%20Cannabis_Patient_FINAL.pdf); and

Clinician Information Resource: <https://www.petermac.org/sites/default/files/media-uploads/Medicinal%20Cannabis%20in%20Cancer%20Clinician%20Resource.pdf>)

DISCUSSION

Developed using a co-design approach, these resources have provided readily available sources of important information for cancer patients and clinicians alike who are considering the use of medicinal cannabis. It seeks to collate and ground the available information in a form that is accessible and meaningful to those who require it.

There is currently a large amount of information and indeed also of misinformation available in the public domain about medicinal cannabis.(18) This was evident in this study where consumer participants suggested they understood medicinal cannabis may be a treatment of cancer itself. This view was also held by 25% of patients requesting medicinal cannabis in outpatient clinics.(19) To directly address this misunderstanding the developed resource states that medicinal cannabis is not a cancer treatment.

We sought to establish the trustworthiness of the information resources using a series of strategies. The co-design approach meant that all views were embedded in the development of the information resources, with participants brought together to hear, discuss and develop consensus. Consumers also highlighted the importance of the resources having authority, which was conferred by the endorsement of the respective hospitals as evidenced by the inclusion of hospital logos.

This project highlighted a dissonance between patients and clinicians, that of who should raise the topic of medicinal cannabis. Reflecting their positioning of medicinal cannabis only when other treatments are ineffective, clinicians did not see it as their role to raise the option. Patients however looked to their clinicians to raise it. The physical locating of resources in cancer service waiting rooms readily available for patients to read and consider, may facilitate this conversation to emerge more readily.

The co-design of a pair of information resources for cancer patients and their clinicians has resulted in an accessible and acceptable resource with content that is relevant and considered important by both groups. Incorporation into clinical practice and distribution around oncology centres has the potential to improve communication about medicinal cannabis in the clinical consultation.

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