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Consumer Contribution in Designing Medicinal Cannabis Clinical Trials in Palliative Medicine

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Abstract

Background: Medicinal cannabis clinical trials in palliative medicine present unique and complex challenges encompassing ethical, legal, and feasibility obligations, making consumer input essential. However, little is known about the consumer contribution in the medicinal cannabis research space.

Objective: We present a case report on consumer contribution in the design and conduct of a Phase I/IIb medicinal cannabis clinical trial for anorexia in people with advanced cancer. Our discussion highlights the various ways consumers contribute through (1) lived experience, (2) knowledge, (3) inclusion as investigators, (4) advocacy, and (5) outreach, considering approaches that can mitigate bias.

Conclusion: Consumer contribution shaped the study design, ensured successful implementation and completion of the trial, and will guide future dissemination of the results. It is crucial that consumers are included at all stages of the research process to uphold research integrity and alignment with future clinical practice and policy.

Clinical Trial Registration: ACTRN12616000516482.

Keywords: anorexia; cancer; clinical trials; consumer; medicinal cannabis

Introduction

Globally, there has been substantial consumer/community, political, and research momentum for using medicinal cannabis to address advanced cancer symptoms, including anorexia.[1–3] Anorexia, characterized by reduced food intake, affects up to 80% of individuals with advanced cancer[4] and leads to weight loss and muscle wasting, which are symptoms associated with cachexia. It is one of the most common debilitating symptoms and contributes to the burden on both the patient and their carers, leading to a reduced quality of life and increased mortality.[5] With limited long-term treatment options available for patients,[6] medicinal cannabis shows promise in improving appetite.[7] However, research in advanced cancer reveals several researcher and consumer concerns including inconclusive evidence,[8] the vulnerability of chronically ill patients, community stigma, future access, and legal status.[9]

While research on medicinal cannabis covers various outcomes,[8] policy,[10] and consumer demand for its acceptance in mainstream medicine,[11] the consumer's contribution in this research space has not been documented. This case reports how consumer contribution informed the design and conduct of a medicinal cannabis clinical trial in an advanced cancer population with anorexia. This is particularly important given new laws for a previously illegal product, which involves a complicated delivery method (vaporization), as

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well as the social and emotional effects of living with cancer-related anorexia.

Case Description

Our trial examined the pharmacokinetics, safety, and feasibility of a delta-9-tetrahydrocannabinol (Δ-9-THC)-dominant cannabis flower bud using a commercial vaporizer in an advanced cancer population experiencing anorexia. The trial was registered (ACTRN12616000516482)[12] prior to data collection, and ethics approval was obtained (HREC/15/HNE/381). This investigator-led trial was supported by the national Palliative Care Clinical Studies Collaborative (PaCCSC), which has an international reputation for conducting scientifically rigorous and consumer-focused trials.[13] PaCCSC has strong governance processes in place to effectively engage and involve consumers in the decision-making process and has an established consumer panel. The consumer panel is recruited through a formal expression of interest process against eligibility criteria, with processes in place for onboarding and ongoing training. Understanding equipoise and identifying situations where new interventions need to be evaluated in a clinical trial context is an important aspect of the consumer training. Carers to individuals with cancer or cancer survivors themselves, from the consumer panel, were invited to help draft the initial funding proposal for two trials on medicinal cannabis in advanced cancer. Two consumers expressed interest and held different roles based on their expressed areas of interest, with both contributing to the study design. One continued as an associate investigator on the trial and participated in meetings with research academics and project staff to assist in problem-solving, oversee the trial's progress, and help interpret the findings. Neither consumer had lived experience with medicinal cannabis, as it was not a therapeutic option available in Australia during their cancer journeys or those of their loved ones, given that the legislation was only changed around the same time the trial was developed.

Five themes outlining consumer contribution in designing and conducting medicinal cannabis trials in palliative populations emerged (Fig. 1). These include the following.

FIG. 1. Overview of consumer contribution in clinical trials.

Consumer lived experience

As a cancer survivor and a cancer carer, one consumer (B.N.) brought a wealth of personal life experience to this clinical trial. However, her role in the trial stemmed from her experience as a carer when her life partner was diagnosed with prostate, bladder, bowel, lung, and brain cancer in 2002. She shared her experience of supporting him during his palliative care journey and highlighted that the decline in physical, social, and psychological functioning affects not only the patient's quality-of-life but also causes distress for carers, who often feel helpless without practical solutions, especially concerning the patient's lack of appetite and reduced food intake. This experience emphasized the complexity of eating and food-related issues, supported by a systematic review that highlighted the challenges carers faced, including anxiety, conflicts with their loved ones, and the time needed to select and prepare food.[14] She disclosed how cooking became a distressing chore; to relieve this stress, she resorted to buying ready-made food only to "throw these in the bin" as this did not change the ongoing issue of appetite loss. It was also acknowledged that this option was not readily available to many carers due to cost. Her insights led the research team to explore the literature on these nuanced issues, allowing them to tailor the intervention and outcome measures—such as cannabis administration, blood sampling, toxicity, appetite rating, and quality-of-life—to address the needs of the trial participants. This approach differs from prior studies, which have focused predominantly on the singular experience of anorexia.[15]

Consumer knowledge

One consumer representative (B.N.) shared insights on the impacts of cancer, discussed experiences with current treatment options for anorexia, such as corticosteroids and progestins, and expressed views on their short-term benefits and potential serious side effects.[16] Recognizing that the assessment and management of anorexia is an unmet medical need for many people with advanced cancer—and their carers—with no long-term treatment options, and its coexistence with other symptoms like nausea and pain, underscored her motivation to help others facing similar challenges.[17–19] Appetite symptoms were integrated with other symptom measures in the trial design, ensuring that the most important measures were prioritized while minimizing those that were less relevant to reduce questionnaire burden. Experience in navigating the health system revealed a lack of a clear pathway for nutritional care and support for many people with advanced cancer. This has been previously identified as a consumer's research priority.[20] The need for accurate information and ongoing support in nutritional care and the use of medicinal cannabis in this population—both for trial participants and those who declined—was also emphasized, prompting the trial team to actively seek out studies, data, or sources that could help ensure a more balanced view and prevent focusing only on evidence that supported existing beliefs.[21]

Consumers as investigators

Two consumer representatives were an integral part of the initial conceptual phase, contributing their perspectives to defining the study population, determining whether the study should be conducted in an inpatient setting, establishing processes for intervention delivery, ensuring safety monitoring, and identifying the outcomes of interest. Their representation and understanding of governance structures were fundamental "in deciding what to research."[19] Their contribution shaped both the initial expression of interest and the resulting funding application and "helped to determine the next steps." The trial team ensured that decisions related to shaping the study and protocol design were grounded in the best available scientific evidence and spent time outlining the current evidence in lay terms to both consumer representatives, enabling them to actively participate with a clear understanding of the available evidence. By focusing on clinically relevant participant-reported outcomes that were well-documented in the literature, the team minimized the risk of prioritizing outcomes based solely on consumer preferences.

One consumer (B.N.) became an investigator, and her participation in meetings provided a platform for sharing both her personal experiences and broader consumer perspectives through discussions with other consumer research representatives. This dialogue informed her contributions to the trial's design. This created a bidirectional education pathway for both the consumer and researchers, helping researchers feel more confident that the study was effectively addressing consumer needs. This structured feedback was used to guide improvements or clarifications.

The recruitment process was not only designed to be inclusive but also adhered to strict eligibility criteria to ensure that the study population reflected those most likely to benefit from the intervention without undue safety concerns. This helped prevent bias in the selection of participants based on consumer-driven preferences for specific subgroups or characteristics. Since the population involved patients with advanced cancer, consumer input was crucial in defining participant attributes. This input considered their ability to manage the study intervention (a vaporized product), undergo continuous blood sampling procedures, and complete both patient-reported and staff-collected data at designated times. These variables could influence decision making about agreeing to be an inpatient for the study's duration and were valuable in guiding trial procedures and optimizing participant completion of the seven-day study.

Consumer representation in the decision to conduct the trial in an inpatient setting was critical, with considerations involving around-the-clock care for participants, and reducing the impact on carers in responding to changes in appetite, food needs and potential side effects. Anecdotally and supported by previous data,[22] medicinal cannabis causes the "munchies" (strong desire to snack) and provided hope to people with cancer who had lost their appetite and chemosensory sensations.[23] From the consumer perspective, one aspect incorporated in the trial was that participants could access food at any time if they experienced the "munchies." This led the trial team to collaborate closely with the hospital food services and carers, ensuring flexibility and responsiveness in providing participants with their requested food items during their hospital stay. The consumer's concern about the risks associated with Δ-9-THC's psychoactive activity, combined with the team's appraisal of previous tolerability data, supported the decision to undertake a single-arm, within-patient dose escalation study.[24,25] To minimize potential bias, the investigator team incorporated a single-blind study design whereby doses were not disclosed to the participants.

Another design change driven by consumer input was the inclusion of "gate leave," allowing participants to leave the trial for personal matters or treatment and return to the site as soon as possible to resume the trial. This helped to retain trial participants and prevented withdrawal. A qualitative component was also incorporated, involving interviews with participants and their carers about their lived experiences of anorexia. It explored the impact of the intervention on these issues, as well as the tolerability and feasibility of the intervention and study design, respectively. This provided valuable contextual information relevant to the outcomes and future trials.[13]

Consumer input ensured that trial-related materials, including participant information, consent forms, and summaries of pending results, were appropriate, easily understood, and accurately conveyed the potential risks/benefits of participation,[26] all while meeting the regulatory requirements of ethical review boards. They reviewed any summaries in lay language, including trial information for the government websites. This drug attracted much controversy in society, and the consumer supported the decision not to advertise the trial in the media to detract unnecessary attention from the participants and recruiting sites. This guaranteed that the benefits outweighed the burden of participation.

Consumer advocacy

Consumer advocacy primarily aims to influence decision makers to effect change, driven by a shared vision of providing societal benefit. This is especially important to address quality-of-life concerns in palliative care.[27,28] Our consumer investigator was passionate about cancer and palliative care advocacy and reinforced her commitment to supporting patients and their carers. This ensured that researchers recognized the broader impact of their work beyond the trial. Despite the limited evidence, there has been strong advocacy for medicinal cannabis use in cancer, partly driven by personal survival stories and, more recently, research highlighting cannabis' effectiveness, better side-effect profile, and increased trust compared with mainstream medicine.[29,30] Initially, this trial presented complex legal, political, ethical, social, and interdisciplinary care considerations within the scrutiny and high expectations of the public eye.[9] The consumers recognized that medicinal cannabis is a political minefield with many opposing viewpoints, and they felt this should be kept separate from the main focus of the trial. As consumer representatives with an understanding of how evidence about medicines is generated in clinical trials, as well as the varying levels of understanding among people with cancer regarding the evidence for medicinal cannabis, they were able to assist the research team in improving communication about the nature of the clinical trial. They emphasized the importance of balancing clear communication about the legalities of medicinal cannabis in healthcare—distinct from recreational drug use, which is not legalized in Australia—with the research question being evaluated and the ethical procedures required in this clinical trial.[31] More importantly, our consumer investigator reiterated that the participant's and carer's decisions were the primary focus in all trial procedures and that outcomes were relevant to both. While consumer input was considered valuable, the trial team sought to balance these perspectives with input from clinical experts, researchers, and regulatory bodies. This helped to ensure that the protocol was developed with a comprehensive understanding of the medical needs, ethical considerations, and scientific rationale rather than being overly influenced by advocacy-driven demands.

Consumer outreach

Given the stigma and controversy surrounding cannabis use,[32] it was crucial to convince our broader consumer base that medicinal cannabis is not merely a recreational drug but a pharmaceutical medicine that needs research to validate its claims. Our consumer investigator prepared us to seek input from various cancer and cannabis advocacy groups, as well as consumers with differing opinions. Input included medicinal cannabis' perceived medical effects, addictive qualities, and increased recreational use following legalization which have shaped policy change.[3] This led researchers to realize the importance of broader consumer involvement to ensure their voices are heard in the trial process and to support medicinal cannabis' acceptance in future clinical practice.

With medicinal cannabis purported as a miracle drug,[33] another issue was tackling equipoise—a clinical trial needs to be conducted with no expectations of whether the intervention is better than current treatment options.[34] Communicating this in the medicinal cannabis space, where there are strong opinions about its efficacy, presents a challenge. Thus, it was important for the consumer to describe the aim of the trial using language that could be understood while protecting the equipoise.[35]

Our consumer was actively involved in several consumer groups and was a member of the executive for Cancer Voices NSW,[36] the state's premier cancer consumer organization, which had established processes and relationships for dissemination and advocacy. This created an opportunity to actively engage with a diverse range of consumers, each with varying levels of knowledge about trials.[37] It also provided a strong platform to educate them on the role of a consumer representative and the importance of evidence-based decisions. The networks reciprocated by advising and supporting our consumer representative, offering insights into how the trial was perceived externally[37] to ensure ongoing compliance. The upcoming dissemination strategy for the trial will require substantial consumer input to ensure that all aspects of the study are communicated effectively to relevant audiences.[19]

Discussion

In studies carried out by the UK Medical Research Council Clinical Trials Unit, being part of the trials management committee meant that consumers undertook a variety of trial-related activities, including protocol design, patient information, consumer advocacy, and outreach.[26] Engaging consumers in the protocol development ensures that studies evaluate meaningful outcomes, enhancing the trial's design, quality, and credibility. This facilitates knowledge exchange between consumers and researchers about the disease's impact[19] while also allowing researchers to gain insight, respect, and rapport with the community.[38] While the trial design included structured mechanisms for gathering consumer feedback at various stages of the study, this input was carefully reviewed by the team in the context of the overall scientific objectives and evidence-based practices. This ensured the integrity of the study was maintained while balancing any potential influences. To prevent undue influence from consumer preferences or advocacy groups, the trial was subject to independent oversight from ethical and governance review boards, various government authorities, and a data monitoring committee. These bodies ensured that the trial maintained scientific rigor while minimizing any potential for bias driven by external interests.

Engagement has been shown to assist with trial recruitment, promote the dissemination and acceptance of research findings in the community using plain language, and help public education, building awareness and confidence in (cancer) research.[19,39,40] Given cancer's poor prognosis, high symptom burden, and its impact on patients and their carers, consumer involvement creates opportunities for the rapid development of treatments and care that align with their needs and priorities.[41,42] Their perspectives ensure that the research respects the community, fostering knowledge and awareness of the condition while giving a voice to benefit the end user.[19,26,38,43]

One limitation noted is the trial's focus on a specific patient population (advanced cancer with anorexia) and the use of a vaporized cannabis product, which may restrict the applicability of the findings to broader palliative care settings or alternative delivery methods, respectively. Harnessing, integrating, and managing the diverse views of consumers were crucial to the trial's successful completion and generation of relevant outcomes to inform future clinical practice and policy. Research should recognize and value the consumer contribution in clinical trials. It is recommended that an overview of their experiences, challenges, and outcomes is provided to improve consumer engagement in future clinical trials.

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No ethical approval was required for this article.

Authors' Contributions

V.R.-N.: Conceptualization, methodology, investigation, validation, formal analysis, visualization, writing—original draft, and writing—review and editing. B.N.: Validation, writing—original draft, and writing—review and editing. L.B.: Resources and writing—original draft. M.R.A.: Project administration, funding acquisition, methodology, supervision, writing—original draft, and writing—review and editing.

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The authors declare no conflict of interest.

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