

Patients' Experiences of Ending Massage Therapy Care: a Commentary

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Patients are best positioned to provide information about their experiences of healthcare services; however, their perspectives are often underutilized. During informal discussions with massage therapists (MTs) and through the authors' own professional experiences, it was noted that there are times when patients decide independently, and without notice, to end the care they are receiving. To date, no research has been published exploring the experiences of patients who choose to discontinue massage therapy care and there is a gap in the quality assurance process of MTs. Lack of understanding of patients' experiences is a missed opportunity to strengthen the therapeutic relationship, ensure patient safety, improve treatment quality, and develop professionally. We recommend researchers explore mixed methods designs, involve patients in the research process, and solicit multiple perspectives when studying patients' experiences of ending massage therapy care.

KEY WORDS: mixed methods; patient-centred; patient safety

INTRODUCTION

Patients are best positioned to provide information about their experiences with health care services; however, their perspectives are often underutilized.⁽¹⁾ If patient feedback is not sought, practitioners may not realize the patient's dissatisfaction with their care,⁽²⁾ which may result in adverse events, poor adherence to treatment, or discontinuation of care altogether. Many patients, dissatisfied with their health care experience, are often hesitant to express their complaints.⁽²⁾ The implication being

that there are more complaints or concerns than are brought to the regulator, health care staff, or the practitioner.⁽³⁾

To date, no published research explores the experiences of patients who choose to discontinue massage therapy care. During informal discussions with massage therapists (MTs), and through the authors' own professional experiences, it was noted that there are times when patients decide independently, and without notice, to end care. Lack of understanding of patients' experiences is a missed opportunity to strengthen the therapeutic relationship, ensure patient safety, improve treatment quality, and develop professionally. Information regarding patient experience would help therapists and clinic owners retain patients and improve the financial success of their practice.⁽⁴⁾

In this article, we discuss the importance of researching patients' perspectives of ending massage therapy care, and the challenges faced during one attempt to conduct such a study. We recommend researchers explore mixed methods designs, involve patients in the research process, and solicit multiple perspectives when studying patients' experiences of ending massage therapy care.

Current Literature Regarding Ending Care

A dearth of literature exists regarding the discontinuation of health care treatments. Where there is research, it often focuses on the practitioner perspective rather than that of the patient.⁽⁵⁾ Furthermore, the existing literature is focused primarily on physicians or other clinicians within more traditional medical practices. It is important to note that we recognized that the differences in context (public vs.

private, traditional vs. complementary or allied) mean that the findings in the studies below may not be transferrable to patients of massage therapists. With that said, given that there is no research focused on patients of massage therapists, we present the existing literature focusing on other health care providers as a starting point. Termination of care is a difficult area of study as “it involves engaging directly with those patients who may feel concerned that their care could be compromised.”⁽⁴⁾ Albeit limited, some studies have captured patients’ reasons for discontinuing care.

Studies with physicians in the United States and Australia about discontinuation of care report a mixture of concerns about clinical care, lack of confidence in the therapist, communication breakdowns, cost or billing, medical records, access, sexual contact, rough or painful treatment, breach of conditions, and discrimination.^(2,3)

The experiences of cancer patients reported by Mazor et al.⁽⁶⁾ found that 30% of patients who experienced a communication breakdown without a concomitant breakdown in medical care believed they had been physically harmed. Fifty-three per cent reported damage to the relationship with their physician. For 30%, this damage resulted in choosing to not see the clinician again.

Knox et al.⁽⁵⁾ reported reasons for termination of treatment with psychotherapists in the United States as completion of goals, lack of confidence in the clinician, lack of progress in treatment, or financial constraints. In their review of the current literature, they noted that “most of the studies used surveys that inherently limited the depth of participants’ responses. We have yet to hear the actual voices of clients describing in rich detail their experiences of therapy termination.”⁽⁵⁾

At the time of writing, no research is published regarding discontinuation of massage therapy care. However, three studies from the complementary and alternative medicine (CAM) literature offer some insight. Kim et al.⁽⁷⁾ investigated factors associated with discontinuation of CAM by Korean cancer patients. Financial burden, lack of effectiveness, harmful events, and physician opposition to the CAM treatment were some reasons for discontinuation. A second study investigated the use of CAM two years after treatment for prostate cancer.⁽⁸⁾ CAM use was less common

than it had been following diagnosis. Participants cited ineffective treatment, harm, physician advice to discontinue, and unsuitability of the CAM treatment to the patient’s preference as reasons for ending CAM therapies.

In the third study, Zanardelli et al.⁽⁴⁾ explored the discontinuation of acupuncture treatments at a clinic in the United Kingdom. Five categories capturing rationales shared by patients: communication, availability, expectations, outcomes, and recommendations. In this study, communication referred to communication about appointments rather than communication, or lack thereof, by practitioners. In contrast to the other studies described above, Zanardelli et al. concluded that when “... patients have discontinued with a therapy service, there is a natural assumption that the therapy has failed or that the service is failing to meet the needs of its users. However, this study has shown the factors that influence discontinuation relate to the access and availability of services rather than the failure of the therapy intervention.”⁽⁴⁾

We believe that patients who end massage therapy care may have similar experiences and rationales to those studied above. We set out to study this phenomenon, given the gap in the literature and variation in conclusions of researchers in other disciplines. This article is not a report on the findings of this research. Rather it is a commentary on our experience and resulting recommendations. During the study, we experienced barriers to enrolling participants that led us to wonder why.

An Attempt to Study Patients’ Experiences of Ending MT Care

A research project was proposed to provide massage therapy patients a forum through which to share their experiences. For the purpose of the study, ending massage therapy care was defined as the point at which the patient terminated the therapeutic relationship with their MT. While some of the reasons may be the same as reported above, a description of patients’ experiences helps to explore similarities and differences for discontinuing care, and can inform MTs’ clinical decision-making and quality assurance process. The research question was, “What are patients’ lived experiences of ending massage therapy care in Ontario?”

Methods

Participants who received massage therapy from a registered practitioner in Ontario, with the intention of returning for continued care, were invited to participate. Individuals who ended care, with at least one registered MT, were interviewed. Participants were recruited by distributing study information to health care clinics in Toronto, Mississauga, Sudbury, and Newmarket, and through word of mouth. Participants were asked to share the researchers' contact information with people who had ended massage therapy care⁽⁹⁾ A sample size of 10 to 12 was anticipated.⁽¹⁰⁾ Data were collected through 45-minute semi-structured interviews. Interview recordings were transcribed. Data analysis was undertaken by both researchers independently and followed Colaizzi's seven-step process.^(11,12)

Challenges

We experienced significant challenges recruiting participants. Once recruited, some were hesitant to, or experienced difficulty in, explaining their experiences. It could be that patient discontinuation is not a pervasive issue. However, these individuals enrolled in a study to discuss their experiences discontinuing treatment. It seemed more likely that they were embarrassed or somehow felt partially responsible for ending care. This lack of enrollment led us to amend our recruitment to widen the recruitment pool from the Greater Toronto Area to all of Ontario. While this modification produced additional participants, we were unable to reach the a priori sample size.

Prior to the study, we were confident we would be able to recruit participants. We had heard stories about discontinuation of care from individuals in our personal and professional circles. However, this confidence quickly faded as the months passed and our recruitment failed to produce the target number of participants.

During the study, when participants were asked to describe an ideal MT, it was easy for them to respond. But, when they were asked to share the experience that provoked discontinuation of care, some responded cautiously. It was difficult to elicit greater detail. We reviewed comments from both potential participants and those whom we interviewed. Because

massage therapy is paid out-of-pocket by patients, it seems that it was felt to be easier to find another therapist than to share the concern/complaint. When concerns were shared with their practitioner, the patient felt their concerns were dismissed or no appropriate action was taken. These statements, albeit only two of many possible reasons for ending care, caused us to wonder what is the best way to research patients' experiences for those patients who may have used silence to resolve their concern? What options exist for researchers to approach this issue in another, more effective, way?

Recommendations for Studying Patients' Experiences of Ending Care

While the outcome of research is intended to be results that can be disseminated broadly, sometimes research studies, such as this one, result in a call to action. This call focuses on researchers. We recommend that researchers explore mixed methods designs, involve patients in the research process, and solicit multiple perspectives when studying patients' experiences of ending massage therapy care.

Consider Mixed Methods Designs

Our study's outcome was such that we were unable to recruit enough participants to publish our findings. While we had heard several stories, when it came to enrolling in a study, many chose to keep their complaint informal. Research using diverse methods to encourage patients' expression of negative feedback is needed. Knox et al.⁽⁵⁾ report that most studies that have been done to communicate patients' perspectives have been quantitative survey-based designs. We wanted to give a voice to patients; this can be limited when using quantitative methods.

We suggest that patients' experiences of ending massage therapy care is big enough, important enough, and messy enough to explore using mixed methods research.⁽¹³⁾ In particular, a sequential explanatory mixed methods design⁽¹⁴⁾ would combine the best that survey methodology and interview methods offer. Such a design would begin with quantitative (QUANT) survey methodology, allowing patients who are concerned about giving negative feedback a safe and structured way to do so. The results of the QUANT

phase would inform the second qualitative (QUAL) phase. Within the QUAL phase, interview methods would be used to explain the results of the first and give voice to the numbers and figures.⁽¹⁴⁾ This mixing of methods promotes the sharing of discomfort and dissatisfaction by patients.^(15,16) Understanding these experiences through research can assist in changes that will alter care in positive ways by bridging the communication gap generated by power imbalance and silence.

Involve Patients in the Research Process

Given the discomfort surrounding sharing negative feedback and the inherent power differential of the patient-therapist relationship, it is worth considering methodologies that involve the patient in the research process. This ongoing shift to include patients and the public in the research process was written about by Dr. Kennedy, Executive Editor/Editor-in-Chief of the *International Journal of Therapeutic Bodywork and Massage*.⁽¹⁷⁾ Her editorial discussed the value of including patients in the research process, which included enhanced participant recruitment and retention.

Involving patients in research shifts the focus from “doing research to” patients to “doing research with” patients.^(18,19) There are different ways patients can be involved. Borrowing from the Smits et al. study⁽¹⁹⁾ that introduces the Involvement Matrix tool, these methods could include listener, co-thinker, advisor, partner, or decision-maker. We are not suggesting one type of involvement is preferable to another. Rather, we recommend researchers consider which type of involvement of patients would be beneficial and at what stage.⁽¹⁸⁾

Solicit Multiple Perspectives

As discussed above, most research to date has focused on the practitioner experience. We believe that the voice of the patient is important in understanding the experience of discontinuation of care. In addition, we propose that researchers seek to identify the current practices used by MTs for soliciting feedback from patients. Developing an understanding of the ways feedback is collected and received, and how that shapes clinical practice, may prove to be useful in contemplating improvements. Additionally, exploring how

patients experience the pursuit of their feedback from MTs may reveal an in-depth understanding how to support and encourage patients of massage therapy to voice their dissatisfaction or experiences of their care.

The current health care literature reveals that voicing dissatisfaction is an uncomfortable and undesirable position in which to be, and we believe that our attempt to understand this phenomenon within the massage therapy context supports this notion. Albeit an incomplete examination, the preliminary findings suggest that more evidence is needed to fully understand the complexity of this issue. Exploring this facet of the therapeutic dyad to uncover potential areas for improvement on the topic of feedback could be well worth the efforts. The knowledge produced from such examinations could inform practice and lead to enhancements of massage therapeutic relationships and of the quality of care.

CONCLUSION

Lack of understanding of patients' experiences is a missed opportunity to strengthen the therapeutic relationship, ensure patient safety, improve treatment quality, and develop professionally. This commentary results from a study in which we were unable to recruit a sufficient number of patients willing to tell their stories regarding discontinuing massage therapy care. We recommend researchers explore mixed methods designs, consider how to involve individual patients in the research process, and solicit multiple perspectives when studying patients' experiences of ending massage therapy care.

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CONFLICT OF INTEREST NOTIFICATION

The authors declare there are no conflicts of interest.

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