



Patient Involvement in Medical Education Research: Results From an International Survey of Medical Education Researchers

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Abstract

There are demands to involve patients in medical education research (MER). This study surveyed researchers to examine the extent and nature of patient involvement in MER. It obtained 283 completed surveys (response rate of 5%). Of the respondents, 153 (54.1%) indicated that they involve patients in MER. Of these respondents, 102 (66.7%) stated that patients are data sources in MER, 41 (26.8%) noted that patients are involved as advisors and/or reviewers, and/or 22 (14.4%) indicated that patients are involved as team members. These respondents reported that they involve patients to improve the relevance of their MER to patients (n = 99; 64.7%), connect MER to patient outcomes (n = 98; 64.1%), and improve the appropriateness of MER (n = 92; 60.1%). The 130 respondents who do not involve patients in MER do not involve them because they believe that their research topic(s) are irrelevant to patients (n = 68; 52.3%), they have limited resources for patient involvement (n = 40; 30.8%), and/or they do not know how to involve patients (n = 28; 21.5%). Researchers need to consider how they can conduct their MER with patients.

Keywords

medical education research, patient involvement, patient outcomes

Introduction

Funding, government, academic, and patient advocacy organizations are encouraging researchers to actively involve patients, their families, and their caregivers (herein referred to as patients) in setting research priorities, defining the scope of research studies, conducting research studies, and disseminating research findings (1-4). Some health-care organizations are also encouraging or mandating patient involvement in research, including medical education research (MER), to promote ethical and democratized research processes (3,5). By actively involving patients in research, researchers are able to undertake research in collaboration with patients and thus, extend patients' roles beyond those of data sources. Patients, armed with experiential knowledge, can contribute unique insights that help align research studies with patients' needs and concerns (6).

However, to date, the research literature has focused exclusively on active patient involvement in clinical and health services research or patient involvement in medical education itself (eg, the teaching of learners) rather than the involvement of patients in MER. Moreover, while

researchers have developed guidelines for actively involving or engaging patients in clinical and health research, these guidelines assume that researchers are always recruiting patients to participate in studies and thus, they focus heavily on active patient involvement in research for the purposes of enhancing patient recruitment and retention (4,6,7). Since MER often recruits learners or educators rather than patients and is distinct from clinical and health research, these guidelines and the existing body of literature is often irrelevant to MER. This lack of guidelines and literature on patient involvement in MER is unfortunate, as patients who are actively involved in MER can help researchers articulate the

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connections between medical education and patient outcomes. Such connections are important because MER often aims to enhance learners' abilities to provide quality health care and ultimately improve patient outcomes (8,9). Therefore, this study explored the active involvement of patients in MER. It aimed to illuminate the extent and nature of patient involvement in this area in order to gather preliminary information to inform future guidelines for active patient involvement in MER. This study focused on answering the following research questions:

1. To what extent are patients involved in MER?
2. How are patients involved in MER?
3. Why are patients involved or not involved in MER?

Method

Sample

Using Web of Science and Scopus, we identified corresponding authors (ie, medical education researchers) who published MER in English in 2017. We selected Web of Science and Scopus because of the number of medical education journals that subscribe to them and because we were easily able to search the affiliations of authors in these databases. In July 2018, we searched Web of Science for all "articles" written in "English" and published in "2017" that were associated with the topic of "medical education." Similarly, we searched Scopus for all "articles" written in "English" and published in "2017" with the term "medical education" in the title or abstract. We exported the full records, which included the corresponding authors' contact information, to an Excel spreadsheet where we removed duplicate author information. This process resulted in the identification of 6416 records that included corresponding authors' information who published in MER in English in 2017.

Instrument Development

To develop the novel survey from scratch, we used published literature on the involvement of patients in health research (3,5,6) as well as on the involvement of patients in health professions education and medical education (8,10). The 15-item survey included closed-ended questions on: (a) MER activities that could involve patients, (b) recruitment and support strategies for patient-researchers, (c) compensation for patient-researchers, and (d) reasons for involving and not involving patients in MER. We piloted the survey with 3 medical education researchers who were ineligible for the study and finalized it based on feedback received.

Data Collection Procedures

Due to the large number of corresponding authors, we used Campaigner, a confidential e-mail distribution system, to distribute the study information letter, survey link, and 2

study reminders. The survey link directed respondents to our survey created in Survey Monkey. To maximize study participation, we followed a modified version of Dillman et al's Tailored Design Method (11) by sending 2 study reminders; one at each 2 and 4 weeks after the initial e-mail distribution. To encourage participation, we also entered interested respondents into an Amazon gift card draw.

Data Analysis

We calculated descriptive statistics (ie, frequencies and percentages) based on the data using IBM SPSS (version 25).

Results

In total, we sent the survey e-mail to 6416 corresponding authors. We received 461 bounce back e-mails due to disabled mailboxes and 204 notifications that the corresponding authors were unavailable during the study period, resulting in 5751 potential survey respondents. We obtained 283 completed surveys, constituting a response rate of 5%.

Respondent Characteristics

The respondents identified their primary roles as professors (n = 83; 29.3%), researchers (n = 64; 22.6%), clinician-researchers (n = 43; 15.2%), clinician-educators (n = 39; 13.8%), clinicians (n = 17; 6.0%), administrators (n = 13; 4.6%), or lecturers (n = 7; 2.5%). Seventeen (6.0%) respondents preferred not to specify their roles. The respondents indicated that their main areas of research are teaching and learning (n = 57; 20.1%), assessment and evaluation (n = 43; 15.2%), clinical skills training (n = 38; 13.4%), curriculum development and/or evaluation (n = 29; 10.2%), intrinsic skills training (n = 19; 6.7%), simulation (n = 16; 5.7%), humanities in medicine (n = 15; 5.3%), or another area (n = 39; 13.8%; eg, including the use of technology, interprofessionalism, leadership, professional development, or admissions). Twenty-seven (9.5%) respondents preferred not to specify their main area of research. Table 1 provides additional respondent demographic characteristics.

Extent of and How Patients Are Involved in MER

Of the 283 respondents, 153 (54.1%) indicated that they involve patients in some form in their MER. When asked what role(s) patients played in their MER, more than half, 102 (66.7%), stated that patients are participants (ie, data sources) in their MER, 41 (26.8%) noted that patients are involved as advisors and/or reviewers (ie, provide guidance to the research team but are not research team members) in their MER, and 22 (14.4%) indicated that patients are involved as research team members (ie, where they are formally recognized as part of the research team) in their MER. When asked about the extent to which and how the respondents involve patients in specific activities of their MER,

Table 1. Respondents' Demographic Characteristics.

| Characteristic | n (%) |
|--|------------|
| Work region (N = 283) | |
| Africa | 6 (2.1) |
| Asia | 43 (15.2) |
| Australia | 20 (7.1) |
| Canada | 32 (11.3) |
| Caribbean | 1 (0.4) |
| Europe (not including United Kingdom) | 51 (18) |
| Middle East | 19 (6.7) |
| New Zealand | 4 (1.4) |
| South/Latin America | 10 (3.5) |
| United Kingdom | 16 (5.7) |
| United States | 65 (23) |
| Prefer not to specify | 16 (5.7) |
| Highest education level (N = 283) | |
| Bachelor's degree | 3 (1.1) |
| Master's degree | 32 (11.3) |
| Doctoral degree | 158 (55.8) |
| Postdoctoral fellowship | 2 (0.7) |
| MD | 70 (24.7) |
| Prefer not to specify | 18 (6.4) |

most indicated that they never involve them in the given activities (see Table 2).

The 153 respondents who involve patients in their MER recruit the involved patients from hospital clinics (n = 81; 52.9%), patient advocacy or support groups (n = 59; 38.6%), inpatient areas (n = 56; 36.6%), community offices/clinics (n = 47; 30.7%), emergency departments (n = 16; 10.5%), community organizations/services (n = 8; 5.2%), patient volunteer groups (n = 4; 2.6%), and/or through other strategies (n = 10; 6.5%). To prepare the patients for their involvement in MER, the respondents provide them with written information about the research (n = 105; 68.6%), discuss the expectations of their involvement with them (n = 84; 54.9%), hold meeting(s)/teleconference(s) to explain the research (n = 63; 41.2%), provide patients with support throughout their involvement (n = 60; 39.2%), and/or provide patients with training to be involved (n = 41; 26.8%). The majority of these respondents expressed that they do not include patients involved in their MER as coauthors on publications, presentations, or posters (n = 108; 70.6%). Approximately half (n = 73; 47.7%) also indicated that they do not compensate patients involved in their MER for their time and expertise (eg, with gift cards or monetary payment).

Why Patients Are Involved or Not Involved in MER

The 153 respondents who involve patients in their MER involve them to improve the relevance of their MER to patients (n = 99; 64.7%), connect MER to patient outcomes (n = 98; 64.1%), improve the appropriateness of their MER (n = 92; 60.1%), facilitate personal benefits to patients

(n = 44; 28.8%), adhere to research ethics board/institutional review board requirements for patient involvement in research (n = 28; 18.3%), adhere to institutional policies that encourage patient involvement in research (n = 27; 17.6%), and/or meet granting agency requirements for patient involvement in research (n = 2; 1.3%). The 130 respondents who do not involve patients in their MER do not involve them because they believe that their research topic(s) are irrelevant to patients (n = 68; 52.3%), they have limited resources to support patient involvement (n = 40; 30.8%), they do not know how to involve patients (n = 28; 21.5%), it is difficult to recruit patients to be involved (n = 26; 20%), they have limited time to conduct their MER (n = 17; 13.1%), it is challenging to communicate their MER to patients (n = 7; 5.4%), patients should not be involved in MER (n = 7; 5.4%), there are too many barriers in the process of involving patients in MER (eg, ethics, protections, documentation requirements; n = 4; 3.1%). Five of the 130 (3.8%) respondents also indicated that they had never thought of involving patients in MER.

Discussion

The purpose of this study was to explore the extent of patient involvement in MER, how patients are involved in MER, and why patients are involved or not involved in MER. At present, many initiatives are promoting active involvement in all forms of research and in research design through dissemination. For example, there is the Strategy for Patient-Oriented Research (SPOR) in Canada, INVOLVE in the United Kingdom, and the Patient Centered Outcomes Research Institute (PCORI) in the United States. These initiatives aim to transition patients from being passive recipients of research to proactive partners who help shape research within various health contexts. To date, researchers have focused only on patient involvement within clinical and health service research. Thus, the present study extended this topic to the realm of MER.

In comparison to clinical and health services research, MER does not always have a direct or causal impact on patients and their health outcomes. However, there is still a strong impetus within MER to demonstrate connections between medical education and patient outcomes, as researchers argue that the effectiveness of medical education is reflected in such outcomes (9). While several of the respondents in this study reported that they involve patients in their MER in order to improve the relevance of it to patients and to connect it to patient outcomes, others indicated that they do not involve patients because they believe that their MER topic(s) is irrelevant to patients. This belief is unfortunate as the education of learners and research on it does affect patients in some form, especially those patients within academic health-care centers where learners provide direct patient care.

While more than half of the respondents reported patient involvement in their MER, the majority of this involvement

Table 2. Extent of and How Patients Are Involved in MER.

| Patients are involved in . . . | N | n (%) | | | | | |
|--|-----|-----------|-----------|-----------|------------|-----------|--------------|
| | | Never | Rarely | Sometimes | Frequently | Always | I don't Know |
| Identifying the research topic | 152 | 42 (27.6) | 33 (21.7) | 41 (27) | 27 (17.8) | 9 (5.9) | 0 |
| Developing the funding application | 152 | 79 (52) | 32 (21.1) | 25 (16.4) | 10 (6.6) | 4 (2.6) | 2 (1.3) |
| Designing the study | 152 | 56 (36.8) | 41 (27) | 33 (21.7) | 13 (8.6) | 9 (5.9) | 0 |
| Planning participant recruitment | 152 | 48 (31.6) | 35 (23) | 38 (25) | 20 (13.2) | 11 (7.2) | 0 |
| Planning data collection | 152 | 64 (42.1) | 28 (18.4) | 29 (19.1) | 17 (11.2) | 14 (9.2) | 0 |
| Developing data collection instruments | 152 | 51 (33.6) | 27 (17.8) | 42 (27.6) | 22 (14.5) | 10 (6.6) | 0 |
| Collecting data | 151 | 51 (33.8) | 23 (15.2) | 34 (22.5) | 27 (17.9) | 16 (10.6) | 0 |
| Analyzing data | 151 | 89 (58.9) | 21 (13.9) | 23 (15.2) | 10 (6.6) | 7 (4.6) | 1 (0.7) |
| Planning dissemination activities | 152 | 53 (34.9) | 24 (15.8) | 35 (23) | 22 (14.5) | 17 (11.2) | 1 (0.7) |
| Preparing manuscripts, presentations, or posters | 151 | 85 (56.3) | 22 (14.6) | 21 (13.9) | 15 (9.9) | 8 (5.3) | 0 |

Abbreviation: MER, medical education research.

is limited to the involvement of patients as data sources rather than active research team members or active contributors to research processes. The literature refers to this limited type of involvement as research being done or to patients rather than with them (12) and as passive involvement (3). The literature also notes that this type of involvement fails to recognize and value the experiential knowledge that patients can bring to research activities (13,14). Therefore, moving forward, it is important for those working in MER to acknowledge that patients, if provided with opportunities, can contribute to, for example, study priority setting, the development of research questions, data collection and analyses, or dissemination efforts. Such active involvement can improve the quality of MER through expanding the range of perspectives that influence its rationales, designs, and other processes as well as increase its relevance to patients (15).

Furthermore, some respondents in this study noted that they involve patients in their MER to adhere to their research ethics board/institutional review board requirements for patient involvement in research or to adhere to their institutional policies that encourage patient involvement. These requirements and policies, which are becoming the norm across many institutions (16), can create conducive environments for patient involvement in MER (17). However, involving patients in MER solely because of such requirements and policies can lead to tokenistic rather than authentic involvement (6,18). Thus, it is important for researchers to involve patients in their MER because they see the morality and value of such involvement rather than doing it because someone or something is mandating or persuading them to do it.

The present study also found that of those who do involve patients in their MER, approximately half do not compensate patients for the time, expertise, or data that they contribute to their MER. This finding is not surprising, as others have also found that researchers rarely compensate patients for their involvement (19) and that the issue of patient compensation is a major challenge (20). Patients involved in research often

do so as volunteers, and the research teams that they are a part of commonly fail to distinguish between the concepts of compensation and reimbursement (19). While reimbursement (eg, for parking, transportation, child care) for the patients involved is good, those in the field of patient engagement recommend that researchers also offer compensation for patients that is equitable to the pay that others on the research team receive (19). Correspondingly, the current study also found that among those who do involve patients in their MER, the majority do not include patients as coauthors on their research outputs. This finding is troubling because if these patients are contributing their expertise to the MER, want authorship, and are meeting authorship requirements, they should be included as authors. Therefore, researchers should be discussing the topics of authorship, reimbursement, and compensation with patients transparently and early on in their MER to ensure that all those involved benefit from such opportunities (19).

On another note, of the respondents who do not involve patients in their MER, many noted that they do not involve patients because of a lack of resources to support patient involvement or that they lack knowledge on how to involve patients. Other researchers have discussed similar findings and indicated that training on how to involve patients in research should be part of researchers' ongoing professional development (13), and that researchers should offer patients training in research processes and terminology (21). In order to provide this training and have access to the abovementioned professional development, researchers need support from funders as well as access to experts in active patient involvement to create strong teams, systems, and networks that support active patient involvement in MER (22).

Notwithstanding, this study has several limitations. For this study, we decided to survey medical education researchers who published in 2017. We chose this approach because we are interested in a wide-range of international medical education researchers' perceptions and reported actions, which may not have been directly observable in their publications (6). Despite keeping the survey short, sending out

reminders, and offering a participation incentive, the response rate for the study was very low. Nevertheless, we recognize that some of the medical education researchers or their institutional e-mail systems may have classified the survey invitation as spam and as such, they did not participate. We also recognize that the topic may have been irrelevant to some of the identified medical education researchers and thus, based on the title of the survey invitation or the description in the study information letter, they may have declined to participate. Moreover, since the survey was anonymous, we were unable to explore the potential of nonresponse bias (23). It is possible that those who did not respond were opposed to or uninterested in involving patients in MER. Furthermore, we acknowledge that medical education researchers who did not publish in 2017 may have expressed additional or different views on the topic. The survey also focused on the respondents' perceptions as well as their self-reported actions on the topic and therefore, they may have provided socially desirable responses and answered the questions more positively than is actually true. However, our assurances to the respondents that their survey responses were anonymous should have encouraged them to provide candid responses. In addition, we did not ask the respondents who involve patients in their MER how many times they involved them in each of the MER studies. It is possible that such involvement was one instance rather than ongoing. Lastly, the survey only included closed-ended items. While these items facilitated data-analysis and made the survey respondent-friendly, they may have limited respondents' abilities to provide additional and more detailed data on this complex topic (24).

Given these limitations as well as the reality that information on how to involve patients effectively within research, in all contexts, is predominately based on gray literature and lacking systematic investigation (16,25), there is a need for future research on this topic. First, it would be valuable to explore patients' perceptions on this topic, especially through a qualitative study, in order to discern if and how they would like to be involved in MER. Second, it would be interesting to use a qualitative case study approach to investigate how medical education researchers are actually involving patients in their research and the impact that such involvement has on the research itself as well as the research team including, the patients involved. Third, as we know from the experiences of those in clinical and health services research, the patients involved in research are commonly affluent and already actively involved in hospital-based advisory groups (25,26) and thus, it would also be interesting to explore how researchers can effectively and meaningfully involve a diverse range of patients in their MER. Fourth, it would be exciting to explore the use of a community-based participatory research approach (27,28), where patients are actively involved in the design, implementation, and validation of a study, to see how it works in MER. Lastly, it would be interesting to investigate if the involvement of patients in MER varies by, for example,

researchers' work regions, professional roles, training, or research interests.

Conclusion

Through a survey of medical education researchers, this study discovered and documented the limited amount of active patient involvement in MER. The findings from this study provide an impetus for developing future guidelines for active patient involvement in MER, especially given increasing demands for such involvement across all health fields. These guidelines along with the abovementioned future research, especially on patients' perceptions of their involvement in MER, will hopefully facilitate and promote patient-oriented or patient-centered MER that highlights the connections between medical education and patient outcomes.

Authors' Note

The research study was reviewed by the University of Ottawa Research Ethics Board. Ethics approval was granted by the University of Ottawa Research Ethics Board on July 6, 2018 (modification approval August 20, 2018). The research study was carried out in accordance with the Declaration of Helsinki (<http://www.wma.net/en/30publications/10policies/b3>), including, but not limited to, there being no potential harm to participants, that the anonymity of participants was guaranteed, and that informed consent of participants was obtained.

Declaration of Conflicting Interests

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