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Perspectives on Patient Involvement from Biomedical Researchers: A Qualitative Interview Study

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Backgrounds: In recent years, there has been a growing trend towards collaboration between researchers and patients, known as patient and public involvement, which has been adopted by many countries worldwide. This study aimed to investigate the perceptions and experiences of biomedical researchers regarding patient and public involvement in research, as well as researchers' perspectives on patient co-authorships.
Methods: A qualitative design was adopted as it is well-suited for investigating the motivations and behaviors of individuals. The study used a content analysis approach with an inductive methodology and a primary data collection method of semi-structured interviews with individuals continuing until data saturation.
Results: Thirteen researchers across a variety of healthcare fields were interviewed. Identified categories included: (1) Expectations of added value, (2) Recognition of authorships, and (3) Identified challenges in research methods. Researchers expressed positive feelings regarding patient involvement and recommended it to other researchers and had essentially no problems with patients obtaining co-authorships. Even though they were positive, many researchers complained about the process being time-consuming and that finding relevant patients at the beginning was somewhat difficult.
Conclusion: Patient involvement in biomedical research can create positive experiences for researchers and provide valuable insights that enhance study design, relevance, and implementation. Despite identified challenges, such as time constraints, recruitment difficulties, and communicative barriers, patient involvement remained overall beneficial.
Keywords: Patient involvement; Research methods; Patient participation.

Introduction

Scientific collaboration between biomedical researchers and patients has been introduced and has increased in recent years[1,2]. Originally emerging in the UK and the US in the late 20th century, this strategy of collaboration has now been adopted by an increasing number of countries[1–3]. The collaboration of researchers and patients is defined as patient and public involvement, in which patients and the public contribute to the design, conception, and/or data analysis of a study, contribute to writing the manuscript, or to other aspects of the research process of a study[4,5]. The National Institute for Health and Care Research (NIHR) provides a more precise definition: it is "research being conducted 'with' or 'by' members of the public, rather than 'to', 'about', or 'for' them"[6].

Plenty of studies have used this novel concept of patient and public involvement, which has brought a paradigm shift in the field of research[7]. For instance, an increased focus on patient and public involvement has been implemented by many journals[8–12] and in different countries internationally[13]. Several studies have highlighted the positive effects of patient and public involvement, including increased recruitment of study participants[14] and a positive impact on the researchers' perception of conducting research with patients[15,16]. Despite the existing literature on this topic, there remains a lack of knowledge regarding the effects on research and researchers with a shortage of understanding of how researchers perceive patient involvement.

Overall, this study will contribute to the existing knowledge of patient involvement. One aspect that has not been extensively investigated is the researchers' perspective on patient co-authorships[7]. Consequently, the aim of this study was to investigate researchers' opinions and experiences regarding patient involvement. Furthermore, we have studied the researchers' opinions on co-authorships in studies involving patients in the research process.

Methods

This qualitative study utilized a descriptive design and is reported according to the Consolidated criteria for reporting qualitative research guidelines (COREQ)[17]. A content analysis approach with an inductive methodology was utilized to examine the collected data for patterns and variations in a categorical manner[11,18]. This approach is useful when knowledge pertaining to a certain idea is fragmented and requires synthesis to provide an

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overview of a given topic[19,20]. The primary data collection method employed in this study was semi-structured interviews, which consists of a pre-determined set of open-ended questions administered to individual participants[20]. The first author, a male medical student working as a full time-researcher with no prior qualitative research experience, was responsible for conducting the semi-structured interviews. He received mentorship and guidance throughout the commencement of the study from a multidisciplinary team of two female researchers (medical doctor, PhD and professor, registered nurse, PhD) and one male researcher (professor, medical doctor, DSc) with extensive backgrounds in both qualitative and quantitative research. The first author had no pre-existing relationship with the participants, and his role as a researcher-in-training was disclosed during recruitment.

Participants with a biomedical research background were recruited as an inclusion criterion, all having experience with patients and public involvement in their research. Convenience sampling was applied in the recruitment process, and participants were selected based on their availability[21]. Of the invited researchers, 13 accepted and 2 declined to be a part of this study. These participants were identified through various methods, such as searching for researchers who have published work in relevant areas and using their contact information from their publications. Snowball sampling was also conducted, in which participants referred other potential participants and provided their contact information[21]. Inclusion criteria for participants were based on the International Committee of Medical Journal Editors (ICMJE), where the researchers must have used patients in their research in accordance with authorship criteria one, being "Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work", and/or criteria two, being "Drafting the work or revising it critically for important intellectual content"[22].

The initial communication was established between the first author and the included researchers via email or phone. Prior to conducting the interviews, participants were provided with a brief informative introduction to the interview, including the interviewer's background in medicine, information about the study's inclusion in a PhD thesis, and that the ultimate goal was to improve the understanding of this field of biomedical research. Participants were also introduced to the type of study, and the study' s aims. Participants were continuously added until data saturation was reached, which was when no new information emerged during the interviews. Interviews were conducted in Danish via phone or video calls.

The first author conducted the interviews from the office, while participants joined from their own homes or another quiet location. Only the first author and the participant were present during the interviews. The duration of each interview lasted approximately 30–45 minutes. An interview guide was developed by the first author, then discussed and edited by the author team. A pilot interview was also conducted by the first author. The interview questions focused on participants' experiences and opinions regarding patient and public involvement, as well as their views on authorship where the patient is credited as a co-author in the byline. The interviews were recorded by a dictaphone and subsequently transcribed and translated into English by the first author. Transcripts were not returned to participants for review or comment, and participants were not asked to validate the final findings. However, the participants could request a summary of the results.

Data analysis was conducted manually by the first author using an inductive approach. This is a method used to analyze and interpret textual data by identifying patterns, themes, or categories that emerge from the data itself, rather than relying on predefined concepts or theories. The absence of software in this process allowed us to engage closely with the data, ensuring a nuanced understanding of the material. Codes were developed through the data obtained from the interviews, and the coding process involved an initial overview of the data through repeated readings of the interview transcripts. This step allowed the identification of key ideas and understanding the essence of the text, forming the basis for codes. Following this, a detailed line-by-line coding process was done, resulting in a deeper engagement with the data and the creation of a more formalized set of codes. These codes were organized into categories and subcategories, thereby creating a conceptual structure that guided the interpretation of the data. Although no formal coding tree was constructed, this way of grouping served the same purpose. The categories and subcategories were then refined through discussions among the author group. Differences in interpretation were resolved through dialogue, ensuring that the categories reflected the data. This manual approach provided flexibility and allowed for the data's complexity to be addressed in depth, thereby enhancing the trustworthiness of the findings.

Prior to the commencement of the study, participants were given written information regarding the study, and then the participants provided informed consent, with the possibility to retract the consent prior to publication. All data collected were anonymized. The study received approval from the Danish data protection agency (registration number P-2022-517) and was exempt from approval by the Ethics committee according to Danish legislation[23]. Additionally, the study was conducted in compliance with the principles outlined in the Helsinki Declaration[24].

Results

In this study, data saturation was reached after conducting 13 semi-structured interviews with biomedical researchers from various healthcare research fields. This section presents the findings derived from the inductive content analysis of these interviews, with categories emerging directly from the data.

The 13 researchers who participated in the study consisted of six male and seven female researchers from diverse healthcare research fields. Their backgrounds spanned a range of research disciplines, including six medical doctors, five nurses, one anthropologist, and one molecular biologist. The researchers were involved in various research areas such as internal medicine, surgery, and diagnostics.

Expectations of added value

Positive expectations and perceptions of patient involvement is the first category that was derived from the data. The primary response from the researchers was a positive inclination towards patient involvement during the initial stages of incorporating it into their research.

"ID03: I had very positive expectations of it. I was expecting that they might direct the research in directions that they thought were relevant and see if it worked out well. I thought that it was relevant to research, so my expectations were quite high."

Other researchers viewed patient involvement as a necessity because of the knowledge the patient could contribute.

ID06: "I simply thought that it was a necessity, and I believed that they had a lot of knowledge that I could utilize."

One researcher expressed the challenge of managing patient involvement in their department and expressed concern over how other researchers might react or respond.

ID07: "It was really difficult.... Being a leader and saying that we should do something is one thing but getting people to actually do it is another. That's why you have to try to get people on board, especially in the department. I thought a lot about how I could make that happen."

Furthermore, besides being very positive about patient involvement, the researchers came up with perceptions of patient involvement and what they recommend others to do. Some researchers speculated that including not only the patients but also their relatives could provide more holistic information due to the relatives' experience and knowledge about living with a person that has a disease.

ID03: "Not just the patients, but also their relatives. Because there are actually some thoughts that we have, and I believe that we should research for their sake, and not for our own."

The majority of the researchers recommended using patient and public involvement, and there were many advices, but one piece of advice from one professor stood out.

ID04: "One should not be afraid. One should think that this could be a gain for everyone. Patients and their relatives should be seen as a strength. Therefore, the advice is, if you haven't tried it before, you should try it. You should have an open dialogue that demystifies both for yourself and the patients."

Recognition of authorships

The second category derived from the data was about co-authorships. Most of the researchers have used patients according to the ICMJE authorship criteria. Most of the researchers in this study used patients for both criteria one and two, but there was a clear distinction that for the majority, the patients were involved in the design of the study fulfilling criterion one only.

ID09: "Yes, in this project it was criterion one.... I have other projects where it's also criterion two, yes. Not everyone wants to be involved all the way, but I also have a project where we have a patient with us. He was with me doing interviews, and has also been a co-author. So he was also involved in refining the article."

Regarding their view on co-authorship, the majority of researchers did not see it as a problem and believed that there was no issue with patients receiving co-authorship if they met the ICMJE criteria.

ID08: "Well, my basic attitude towards authorship for patients is the same as it is for authorship from colleagues, which is that if they meet the ICMJE criteria, then I don't see anything wrong with them being co-authors."

Some researchers mentioned that while patients had the opportunity to be co-authors, they were not necessarily interested in an authorship. They did not have the same level of ambition or desire to publish as the researchers did. Instead, they simply wanted to make a difference in the research and contribute to its development.

ID11: "So I think that for researchers, it gives us points on our CV and advances our research career to have scientific publications, but it doesn't have the same meaning for patients. I don't think it's as meaningful for them. They can say they have contributed something, but I feel that our patients are just as proud to be out there, to have contributed to developing this intervention and making it better…. That's what they are passionate about."

Generally, researchers from the interviews expressed that they did not believe that patients involved in research needed additional qualifications to achieve authorship. The ICMJE criteria for authorship[22] were seen as sufficient. This is because most patients involved were already resourceful individuals from strong backgrounds, meaning they had high education, English language proficiency, and had the spare time to engage in research and there was no need for additional qualifications to be set for them to achieve authorship. One of the interviewed researchers even reported a case where a patient served as the lead author of an article.

ID12: "No, I don't think so. I think it's up to the researchers to make the material they need or read through it, if this is about making it accessible for patients. It's not their responsibility to meet certain criteria. I think we have to be very careful not to exclude certain groups and populations from research activities.... "

Identified challenges in research methods

In general, a few challenges occurred. These challenges included the time-consuming nature of patient involvement, recruitment issues, and communication problems. Almost all researchers mentioned that patient involvement was time-consuming. It was time-consuming to find the patients, conducting preliminary work before involving them in the research, and accommodating the patients by booking rooms, providing food and beverages, and so on.

ID09: "Well, it's time-consuming. There's a lot of logistics to take into account, and we need to ensure that the patients are comfortable."

ID12: "But I don't know if it's a negative thing or a challenge. It's just incredibly important that people don't get frustrated about having to do something they're not completely sure about, or that they have to do it like everyone else when they participate in a project. We need to have the same idea of what we're working on."

Some experienced communication problems with patients. Although they did not stress much about this area, most of the researchers explained that much of what they had to do was to prepare themselves to explain their project and other relevant areas of the research to the patient in a way that could be understood by them.

ID04: "Involving patients or relatives, whether in molecular or clinical research, requires being able to engage and inform them about the project and their role in it. Otherwise, they cannot provide their valuable input."

Even though the researchers experienced that it was time-consuming and that it was hard to find the patients in the beginning, almost all researchers were positive about having patients involved and stated that it gave them new and valuable perspect-

ives on their research. Furthermore, they did find the patients' perspective relevant and that it made a change for them as researchers and in their research.

ID06: "Then I was also hugely impressed at times when I presented my findings and they could give me some perspectives that I hadn't even seen. So, I said that they had put on glasses to some perspectives that I just didn't have at all."

Some researchers reported that initially, they did not know where to recruit the relevant patient, but it became easier after the first few contacts were made. Furthermore, some researchers mentioned that they had patient boards, making it easier. However, in general, recruitment was done in various ways. The researchers found patients in the clinic, patient organizations, patient boards in the hospital, through social media, or by snowball sampling.

ID09: "We recruited through a patient association, advertised via the patient association. Initially, I believe we selected four people to be part of a steering group for projects or a project group, simply at an organizational level, and had them involved. In other projects, it has been clinicians who already had knowledge of these patients, who recruited through their clinical practice. In reality, it has typically been something that one has had the opportunity for through the internet, of course with all ethical precautions. We have a fantastic user panel, which I believe is called the User Council, but it is actually a panel, a standing database with a number of our patients, who we call users, and their relatives."

Discussion

In this qualitative study about opinions and experiences regarding patient involvement from the researchers' perspective, we found that the researchers had expectations of added value, that patients could be recognized as co-authors, and that there were identified challenges in research methods when patients were actively involved.

In the past few years, there has been a growing interest among biomedical researchers in patient involvement, which can be traced back to the 1970s[25]. In our study, we discovered similarities with other studies[15,25–28]. For instance, one such similarity is how patient involvement widened the focus and facilitated new research agendas[15,28]. Some studies have reported that involving patients in research requires a substantial time investment from the researchers and patients, which can subsequently affect the research process[25,27,28]. In our study, we found that researchers indeed meant that involving patients was a time-consuming task, e.g., due to logistical planning, patient recruitment, and communication problems. Nonetheless, other studies have reported that involving patients had a meaningful impact and that their inputs were inspiring and valuable[28,29]. In addition, we found that researchers had experiences of added value when involving patients.

Exploring the concept of co-authorship, particularly with respect to the ICMJE authorship criteria in this article, has to our knowledge not yet been assessed in this manner or using this method. In addition, a recent commentary was published that provides practical guidance for researchers and patients on how to approach co-authorship for patients[30]. Essentially, it states that for patients to be co-authors, contributions according to the ICMJE criteria must be fulfilled[30]. Furthermore, researchers are recommended to have a conversation with the patient about authorship early in the research process[30]. This presents an intriguing angle given the significance of patient rights. The need for a deeper exploration of patients' views on this issue is needed. However, the general involvement of patients in research is low. For example, in the surgical field, a recent review found that only 12 studies representing 1.7% of the surgical studies from major journals during the year 2021 had used patient involvement, and in those 12 studies, only one patient in one study had achieved co-authorship[31].

Regarding the involvement of patients in the research process, a common issue that emerged in this study was that the usual flow of a study was changed. This has also been reported in a systematic review[26]. Apart from the time-consuming nature, it is important not to overlook the challenges related to recruitment and communication with patients. Researchers should be mindful of whom they recruit, how they recruit them, and how they communicate with them, which also has been reported in other studies[25,26]. Despite the existence of these challenges, it is crucial to acknowledge the positive impact that patient involvement can contribute, such as expectations of added value for the researcher and the overall dynamic of the research[25,28].

This study adhered to the COREQ guidelines[17], which set a standard for reporting qualitative research. We made a conscious effort to include participants from various fields of healthcare research, thereby providing a broader overview of patient involvement. However, certain limitations of this study should be acknowledged, including challenges in participant recruitment, selection bias (since only biomedical researchers with experience with patient involvement was included), and potential issues related to transferability, and the absence of direct questioning about why or why not patients fulfilled individual authorship criteria. The positive predisposition our participants had towards patient involvement might have prompted some to intentionally provide positive feedback. Additionally, the analysis could have been strengthened by involving another independent researcher in the coding process. However, due to resource limitations, categories were refined, and differences in interpretation were resolved through discussions among the author team. Finally, while similar studies on patient involvement have been conducted with participants other than researchers[32], further research is needed to fully understand the various aspects of patient involvement. Future studies should focus on developing effective strategies to simplify recruitment, improve communication with patients, and ensure that involvement is both inclusive and diverse. To gain a better understanding of patient involvement, it will also be important to investigate the perspectives of researchers who have refrained from involving patients, experienced negative outcomes, or explicitly rejected patient involvement in their study design. Additionally, comparative studies are needed to evaluate the impact of patient involvement by comparing outcomes between research conducted with and without such involvement, and by examining the contributions and viewpoints of both patients and researchers. Finally, long-term studies should explore how patient involvement influences the translation of research findings into clinical practice and how it affects overall research quality. This approach will help identify the most effective strategies for implementing patient involvement in research.

Conclusion

From the interviews with biomedical researchers, we found that they had expectations of added value, recognition of authorships, and identified challenges in research methods. Generally, researchers exhibited a positive response to patient involvement and co-authorships and believed that it had a beneficial effect on both them and their studies. However, several challenges were identified, including time consumption, recruitment difficulties in the initial phases, and potential communication problems that could hinder patients' full understanding of the studies or other aspects of the research process.

Abbreviations

COREQ guideline, COnsolidated criteria for REporting Qualitative research guideline.

Ethical approval and consent to participate

All data collected were anonymized. The study received approval from the Danish data protection agency (registration number P-2022-517) and was exempt from approval by the Ethics committee according to Danish legislation.

Conflicts of interest

All authors declared that there are no conflicts of interest.

Authors' contributions

ZMM: conception, design, acquisition, analysis, interpretation, wrote the manuscript; SÖ: conception, design, analysis, interpretation, revision. HK: design, acquisition, analysis, interpretation. JR: conception, design, analysis, interpretation, revision.

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