Engaging family partners in deceased organ donation research—a reflection on one team’s experience

Impliquer les partenaires familiaux dans la recherche sur le don d’organes : réflexion sur l’expérience d’une équipe

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Received: 20 June 2018 / Revised: 4 October 2018 / Accepted: 4 October 2018 / Published online: 28 January 2019

Abstract

Purpose Clinical researchers are now encouraged to include patient partners in all research projects. Nevertheless, published accounts of patient engagement in complex research projects, such as those involving critically ill and dying patients, are lacking. Whether this absence is due to the relatively new emergence of patient engagement research methods or fundamental challenges regarding family engagement in challenging research contexts is unclear. We describe our experiences with forming a researcher-family partnership in a deceased organ donation research project involving the prospective observation of potential and actual deceased organ donors dying in the intensive care unit.

Methods We used the Guidance for Reporting Involvement of Patients and the Public evidence-based, consensus-informed reporting guidelines to organize our narrative.

Results We were able to initiate and sustain a research consultant relationship with the mother of a deceased organ donor for over two years. Challenges faced included: constraints on money and time, communication preferences, and the emotional stress of participating in difficult conversations. Positive outcomes included: improvement of data collection tools, new opportunities for access to research populations, and motivation to include family partnership in future grant proposals.

Conclusions Family engagement in deceased organ donation research is feasible and contributes positively to study progress and outcomes. Patient and family engagement in challenging research contexts may require special attention to the emotional challenges of

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participation. We hope that our experience will encourage clinical researchers working in deceased organ donation and similarly complex domains to consider including patient partners in their projects.

Résumé

Objectif Les cliniciens sont maintenant encouragés à inclure les partenaires des patients dans tous leurs projets de recherche. Néanmoins, on ne dispose d’aucune publication sur la participation des patients et de leur famille dans des projets de recherche complexes tels que ceux impliquant des patients dans un état critique ou mourants. Savoir si cette absence est liée à l’émergence relativement récente des méthodes de recherche sur la participation des patients ou aux défis fondamentaux concernant la participation des familles dans un contexte de recherche difficile reste une question débattue. Nous décrivons nos expériences de la formation d’un partenariat chercheur-famille dans un projet de recherche sur le don d’organe impliquant l’observation prospective de donneurs d’organes potentiels ou décédés, décédant dans une unité de soins intensifs.

Méthodes Nous utilisons le document intitulé Guidance for Reporting Involvement of Patients (conseils pour rendre compte de l’implication des patients) et les lignes directrices publiques basées sur des données probantes pour la publication fondées sur un consensus, pour organiser notre compte rendu.

Résultats Nous avons pu instaurer et maintenir pendant plus de deux ans une relation de consultant en recherche avec la mère d’un donneur d’organe décédé. Les défis rencontrés étaient notamment les contraintes financières et de temps, les préférences en matière de communications et le stress émotionnel créé par la participation à des conversations sur des sujets difficiles. Les résultats positifs ont été, notamment l’amélioration des outils de collecte de données, les nouvelles possibilités d’accès à des populations de recherche et la motivation à inclure un partenariat avec la famille dans les futures propositions de subventions.

Conclusions La participation de la famille dans la recherche sur le don d’organe d’une personne décédée est faisable et contribue positivement à l’avancement et à l’aboutissement des études. La participation du patient et de sa famille dans un contexte de recherche difficile peut demander de porter une attention particulière aux défis émotionnels de cette participation. Nous espérons que notre expérience encouragera les cliniciens chercheurs qui travaillent sur le don d’organes de personnes décédées et d’autres domaines aussi complexes à envisager d’inclure les partenaires des patients dans leurs projets.

Pressure has increased for Canadian clinical research projects to include patient engagement strategies.1,2 Patient and family engagement in health research is a process whereby patients and those with personal experiences of a health issue (including caregivers and family members) move from being passive research subjects to active participants in research design, governance, priority setting, and knowledge translation.3 Patient engagement in clinical research has improved participant recruitment and knowledge translation activities.4,5 Participant involvement in research has a long history in the social sciences,6 but the approach has been met with skepticism from some clinical researchers.7 Might there be certain areas of clinical inquiry where meaningful patient engagement is not possible?

Complex research designs involving critically ill patients and their families, for example, present unique challenges to traditional models of patient engagement activities. Critical care research often involves short-term interactions with distraught family members at an emotional time. Study designs may involve enrolment of critically ill patients during the process of active resuscitation or during the dying process in the intensive care unit (ICU). Research teams are thus unable to integrate patient partners through long-term clinical interactions as is possible with chronic disease and health services research. Instead, research engagement must focus on patients’ families, and must be sensitive to the stresses these families confront as part of caring for a critically ill or dying relative. Nonetheless, despite the methodologic hurdles of ICU research and the involvement of grieving families, we hypothesized that patient engagement in these types of projects would be feasible. Moreover, we also anticipated that engagement would require special considerations beyond those recommended by current best practices.8 In this paper, we describe our experience with forming a researcher-family partnership on a project involving prospective observational research of patients dying in the ICU.

Methods

Our family partner was actively involved in the discussions and reflections required to write this manuscript. We used the Guidance for Reporting Involvement of Patients and
the Public five-item short-form reporting guidelines to organize our engagement narrative as it occurred within a larger scientific study. Our experiences with family engagement are reported across five domains: 1) aim of family engagement in the study, 2) methods used for family engagement, 3) positive and negative results of family engagement, 4) extent to which family engagement influenced the study overall, and 5) critical commentary on the family engagement experience, with summarized insights for others.

The research project

The Death Prediction and Physiology after Removal of Therapy (DePPaRT) study is a prospective, observational cohort study of patients (including potential organ donors) who die following the controlled withdrawal of life sustaining therapies in the ICU. It was first approved by the Children’s Hospital of Eastern Ontario Research Ethics Board on May 1, 2014 (CHEOREB#14/08E). The main objective of the study is to measure the incidence of clinical autoresuscitation (unassisted, spontaneous resumption of circulation following the declaration of death). A subsumed study includes interviews about decision-making with families approached for their consent to organ donation.

The family partner

Six years before one of the author’s (H.T.) involvement with the DePPaRT study, her 22-year-old son Jonathon sustained severe head trauma as a passenger in a motor vehicle accident. He was rushed to ICU but did not recover from his injuries. The decision was made to remove Jonathon from life sustaining therapies and to donate his organs. At the time, H.T. recalls feeling ambivalent about organ donation, only agreeing at the insistence of her daughter, who had discussed the subject with Jonathon and remembered he had signed his donor card. H.T. also spoke to a rabbi to make sure organ donation was not against her religion. The rabbi assured her organ donation would be a mitzvah, a good deed. Jonathon donated his liver, lungs, kidneys, and heart valves, saving at least four lives and providing H.T. and her family with the feeling that “something good came of something bad.”

After Jonathon’s death, H.T. felt she needed to do something creative and productive with her grief to honor her son’s memory. She became engaged with local and national organ donation and transplantation organizations where her warm personality and networking skills quickly made her a well-known figure. In November 2015, H.T. was invited as a member of the organ donation and transplantation community to participate in an initiative to set research priorities. For H.T., involvement in organ donation research was an extension of her ongoing community and advocacy work.

Aim of patient engagement activities

The primary aim of patient engagement activities in the DePPaRT study was to obtain consultation and feedback about study procedures from a family member’s perspective. We hoped that this would help generate ideas about how study procedures, which require consent from family members of dying ICU patients, could be improved to facilitate research staff buy-in and increase rates of patient enrolment. In addition, forming a family partnership would likely be beneficial for future protocol development and for designing family-centred outcomes.

Methods used for family engagement

Two major steps in the methodology of patient and family engagement are identification and recruitment of a suitable family partner, and their integration into research activities. The study team was assisted significantly in the implementation of both of steps by the Canadian National Transplant Research Program (CNTRP), a federally-funded network of researchers, clinicians, patients, and stakeholder organizations in the organ donation and transplantation community, which has established a strategy for patient engagement in research. Our study team benefited greatly from the mentorship of core CNTRP researchers (including one of the authors, M.C.F.) that focused on patient engagement in research.

Family partner identification

We began by developing a list of criteria for a suitable family partner (Table 1). We aimed to make our criteria broad enough to capture a large population of potentially interested participants, and specific enough to identify the best possible fit for this unique project. We felt purposive sampling within an existing community of family members and patients interested in the organ donation and transplantation community would be most efficient for identifying a candidate with the desired characteristics.

Purposive sampling occurred with the assistance of the CNTRP, who connected us by email with one family member (H.T.) who had already participated in a patient and family engagement activity. Email correspondence between H.T. and the study team led to an introductory phone call, during which the group introduced themselves and the clinical research study, and discussed anticipated goals for family partnership (i.e., consultation on study.
procedures). H.T. also introduced herself and provided an informal overview of her skills and volunteering experience. Throughout the call, the study team emphasized the optional, voluntary nature of family engagement in research. No formal time commitments or plans for research participation were made. The call was emotional as H.T. explained the circumstances of loss through which she became involved in organ donation communities. All participants were prepared for a sensitive conversation and felt that openly sharing emotional experiences was an important step towards building a strong partnership. This introductory call and resulting follow-up emails served to establish the group’s commitment to the research cause and to collaboratively generate opportunities for H.T.’s involvement. These preliminary interactions also helped the study team confirm that H.T. met all pre-determined family partner criteria (Table 1). Purposive sampling helped to identify one potential family partner, who met the criteria for involvement. Our team decided not to contact other family partners until our partnership with H.T. was well-established.

**Results of family engagement**

Over the course of additional phone calls and one face-to-face meeting, a collaborative plan for family partnership emerged. We presented to H.T. opportunities where we felt her perspective as a deceased donor family member and her skills as a community advocate would be most helpful. H.T. then chose to engage (or not) with these activities as her time and interest permitted. Both H.T. and the clinical study team were satisfied with this partnership arrangement. Our family partnership activities consisted of a combination of relationship building and research undertakings (Table 2).

Family partner involvement in the DePPaRT study has led to improvements in study design and changes to study procedures. H.T. has encountered emotional and technical challenges as part of her participation, and the study team has also faced challenges including limited time, resources, and experience with such family engagement activities. Nonetheless, both parties agree our partnership has been beneficial.

**Positive outcomes**

H.T.’s involvement has positively affected study design, recruitment materials, stakeholder buy-in, and data collection tools, as described in Table 3. Although H.T.’s son was not enrolled in research, H.T.’s ability to reflect on her family’s experiences and critically appraise proposed study procedures has been an invaluable resource for improving our study design. The perspectives provided by H.T. have helped us change wording in study documents and assuage fears of overstepping boundaries with research procedures. Her presence at meetings also provides energizing immediacy to the relevance of our work.

**Challenges**

We faced a number of challenges with our family engagement strategy. First, we did not have prior experience with patient engagement activities. Second, we were unable to find published literature about patient engagement activities in the context of deceased organ donation. Third, our grant-funded team lacked financial resources to allocate specifically towards family engagement activities. Fourth, H.T. experienced grief during the emotionally laden nature of discussions about organ donation and death, and fifth, H.T. was confronted by the technical requirements (such as emails and teleconference calls) of participating in a clinical research team.

Our study team worked together to surmount these challenges. We rearranged our financial resources to allocate funds for face-to-face meetings. H.T. insists that despite the emotional toll of the research topic, she still feels good about contributing to positive change through research. The clinical research team has made a conscious effort to be sensitive in our discussions, and H.T. feels well-supported and accepted by the study team. Finally, we

| Table 1 Mandatory criteria for a family partner in deceased organ donation research |
|---------------------------------|---------------------------------|---------------------------------|---------------------------------|
| **Personal characteristics**    | **Lived experiences**           | **Mandatory criteria to be met** |
| Lives within 1-2 hours travel from central research team location | Experiences of consenting to deceased organ donation | Lives within 1-2 hours travel from central research team location |
| Fluent in English               | Experiences of losing a loved one in the intensive care unit | Willingness and ability to engage with research topics around death, intensive care units, and organ donation |
| Willingness and ability to engage with research topics around death, intensive care units, and organ donation | | Willingness and ability to participate in regular research meetings (usually by phone) |
| Willingness and ability to participate in regular research meetings (usually by phone) | | |
have made special efforts to accommodate her preferred means of communication and to simplify technical requirements for meeting participation (e.g., using phone instead of webinar).

## Discussion

Despite our challenging research topic and the special considerations required for patient engagement activities,
we have successfully integrated a patient family member into our clinical research team. Engaging a family member in this unique critical care project has been feasible despite the emotional aspects of our work. Our engagement strategy has led to meaningful improvements in study design, recruitment materials, stakeholder buy-in, and data collection tools, in addition to lending credibility to our study approach and helping to engage multi-site research teams. Our experiences echo those of Sofolahan-Oladeinde et al., who describe positive experiences and local challenges at the start of their foray into patient engagement activities.17

We found family engagement in deceased organ donation research faces similar challenges, such as limited time and resources,5,12,17 as those reported in other research contexts. We also identified a new challenge posed by grief of family members with experience of deceased organ donation. We have contended with this challenge by providing a supportive environment that includes active listening, allowing additional time for processing information, and providing opportunities for breaks and questions. We did not offer nor did H.T. request any formal institutional support (e.g., access to counseling). H.T. has suggested that including another family member with similar experiences would be beneficial for improving family partners’ ability to cope with difficult discussions, a recommendation we have since implemented. Lasting emotional trauma is common in family members with experience caring for a loved one in the ICU18,19 and we anticipate this challenge would be generalizable to other clinical ICU research groups attempting to incorporate a family partner.

Limitations

Our family partnership strategy has included only one family partner, working at a “consultative” level of engagement.20-22 While some may label this as “tokenistic”,23 we have found that taking time to build a strong, personal relationship with a family partner has been worthwhile in fostering meaningful participation and engagement. First, by upholding a “consultant” level of engagement, H.T. has maintained her invaluable expertise as a “lay” participant in our team.24 As a result of our relationship, H.T. feels she can contribute thoughts, ideas, and suggestions about the project, and her contributions are valued. In addition, she has contributed as a “consultant” in family experiences of deceased donation at multiple levels of the organ donation and transplantation research community. Assumptions about “tokenism” may downplay the value family partners ascribe to research participation.25 We argue that despite involving only one

Table 3 Results and research outcomes of family engagement activities

| Domain of engagement | Results of engagement | Research outcomes |
|----------------------|-----------------------|------------------|
| Study design         | H.T. provided critical, reflective perspective on study process of asking for research consent at the time of a loved one dying in ICU | Endorsed acceptability of prospective consent design from one family perspective |
|                      |                       | Helped to mitigate concerns from research coordinators that they were being intrusive by asking for consent so close to death |
| Recruitment materials| H.T. provided constructive comments on pamphlet designed to provide information about the study to distraught families | Changed wording of pamphlet to be more understandable and easily readable in a waiting room |
|                      |                       | Modified design to include images |
| Stakeholder buy-in   | H.T. provided a point of contact for her large community networks of potential stakeholders and research participants (for qualitative sub-study) | Facilitation of relationship with potential communities for further partnership |
| Data collection tools | H.T. participated in a pilot interview about family experiences with end-of-life decision-making | Modified interview guide to improve understandability of questions. Removed questions deemed not relevant to family decision-making experiences. Added follow-up questions to ensure all relevant information discussed during participant interviews |
| Meeting participation| H.T. attended small and large study-group meetings, including some with international stakeholders. H.T. asked questions and participated in discussions about study design, progress, and analysis | The presence of a donor family member made meeting discussions immediately relevant. H.T.’s insights about what information would have been helpful or hurtful to her family during her son’s death helped to foreground opportunities for future research |
|                      |                       | Active and engaged presence of a family member also encouraged other research groups to become interested in family engagement strategies |
family partner, the alignment of our expectations with H.T.’s participation has led to a mutually beneficial engagement in addition to improved study design, streamlined recruitment materials, increased stakeholder buy-in, and improved data collection tools.\textsuperscript{26} While we feel that engagement with just one family partner helped us to build a strong working relationship, we also recognize the limitations imposed by including a single voice at different stages of the design process.\textsuperscript{27} We acknowledge that H.T.’s opinions and personal experiences are not representative of all donor families. Nevertheless, we believe that legitimate recognition of one voice is inherently more beneficial than the absence of any family partner contribution. In addition, H.T.’s involvement has modified the way our research team functions and has helped to ensure that inclusion of family partner voices becomes routine practice. Finally, the family partnership strategy we have built with H.T. has helped us to incorporate additional family partners into our team.

Conclusions

Our experience with patient engagement activities suggests that family engagement in deceased organ donation research is feasible and contributes positively to study design and outcomes. Despite the sensitive nature of research on dying populations, engaging families about how research can and should be done is important for improving the quality of research and ultimately for improving quality of care. Our success with family engagement in deceased organ donation research suggests fruitful approaches to patient engagement in research are possible even during difficult circumstances. We encourage clinical researchers working in organ donation and transplantation and similarly complex environments to consider including patient partners in their projects. For this to become widespread practice, it is crucial that researchers report on this aspect of their research project design.

Acknowledgements We would like to thank the Canadian National Transplant Research Program for their ongoing support of our family engagement initiative, and the Talbot family for generously sharing their experiences and their time with our research team. Canadian Blood Services and the Canadian National Transplant Research Program supported the cost incurred for Open Access Publishing for this manuscript as both organizations actively promote and support patient engagement initiatives within the areas of organ donation and transplantation throughout their organizations.

Conflicts of interest None declared.

Editorial responsibility This submission was handled by Dr. Steven Backman, Associate Editor, Canadian Journal of Anesthesia.

Author contributions Amanda van Beinum participated in research design, performing the research, analyzing the data, writing the paper, and coordinating submission for publication. Heather Talbot, and Laura Hornby participated in research design, performing the research, analyzing the data, and writing the paper. Marie-Chantal Fortin participated in providing feedback on the paper. Sonny Dhanani participated in research design, performing the research, and providing feedback on the paper.

Funding sources The Canadian National Transplant Research Program generously contributed funding to part of our family engagement initiatives. The Canadian National Transplant Research Program and Canadian Blood Services supported the cost of Open Access Publishing for this manuscript.

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