COMMENTARY

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Overcoming challenges in research on self-managed medication abortion: lessons from a collaborative activist–researcher partnership

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A new collaboration: background

Throughout history, across cultures, and continents, people have had abortions. Historically, people relied on a range of methods to terminate unwanted pregnancies, from herbs and massage, to physical trauma and ingestion of toxic substances[1] – sometimes on their own, sometimes with support from a healer or trusted person. Surgical abortion entered the realm of options during the 1700–1800s and helped to make abortion safer than many alternatives, but also prompted a major shift of abortion care from something that was self-managed, to something that was medicalised.[2] The advent of safe and highly effective medical abortion in the late twentieth century, however, marked a turning point yet again. Medical abortion (misoprostol alone, or in combination with mifepristone) offered a glimpse of a new future, one in which safe, effective abortion practices could be self-managed, rather than needing to rely on clinical intervention or supervision.

Since the discovery of the abortifacient properties of misoprostol by women in Brazil, and the advent of mifepristone, decades of rigorous research have established the safety and effectiveness of medical abortion in clinical settings.[3] When these medications are accessible, a safe abortion can be as easy as taking a few pills. Yet, legal restrictions, logistical factors, and stigma impede or prevent access to these medications throughout much of the world. Where legal restrictions create barriers to abortion access, people must find their own ways of ending a pregnancy outside of health facility settings.[1] Even in countries where abortion is legal, people self-manage abortions because they cannot afford or otherwise access clinical care, or because they prefer the experience of a self-managed abortion for reasons of privacy, security, and/or experienced stigma.[1]

Initially frustrated by the persistent harms experienced by women and pregnant people as a result of unsafe abortion methods, activists around the globe, in a variety of legal contexts, decided to do something.[4] In Argentina, Nigeria, and more than fifty other countries, activists – known often as "accompaniers" – provide information and support to people seeking to end a pregnancy. Known as safe abortion hotlines or feminist abortion accompaniment networks, these groups provide evidence-based information[3] to pregnant people on how to safely use medications to end a pregnancy.[5] These groups aim to provide information and support in a way that empowers, validates, and affirms

each person while also educating them about their body – transforming the traditional patriarchal hierarchy of the clinician–patient relationship to an egalitarian, feminist model of peer-to-peer education.[4] As well as providing accompaniment support to people through the abortion process, many accompaniment groups lobby governments and lawmakers to liberalise abortion laws, and build relationships with local clinicians to expand safe abortion options.[6]

Activists who provide accompaniment for self-managed abortion day in and day out, possess decades-long experiential knowledge of the effectiveness and safety of this model, and understand its power and promise to transform access to safe abortion. Yet, these same activists appreciate that their own lived experiences may not have the power to shape programmes, laws, and policies related to self-managed abortion without peer-reviewed research to back them up. Similarly, trained researchers can design rigorous research to evaluate the safety of self-managed abortion, but without activist partners, generally lack access to people pursuing self-management due to the clandestine nature of the activity and corresponding concerns about legal and privacy risks, and thus struggle to enrol participants.

Leveraging the shared goal of systematic research on self-managed abortion, researchers and accompaniment groups have begun to explore if and when research collaboration can advance knowledge and understanding. In this commentary, we share the experiences and perspectives of activists and researchers in the development of a collaboration designed to collect transformative evidence about people's experiences self-managing abortions with accompaniment group support, as well as the safety and effectiveness of the model. We consider this through the stages of the partnership from formation to structure and process to lessons learned.

A new collaboration: formation

Recognising that self-managed medical abortion with accompaniment support is an increasingly visible and salient model of abortion care[5] with great promise to expand access to high-quality abortion regardless of legal setting, we have explored partnerships between researchers and accompaniment groups to document this model and raise awareness. Over the past decade, we have built collaborative, activist–researcher partnerships to describe safe abortion hotlines and the accompaniment model of care in the peer-reviewed literature – work that has outlined the model, evaluated innovative approaches to providing people with support, explored experiences of self-managed abortion in later pregnancy – and has, to date, built a foundation of evidence on the importance of the accompaniment model in centring the experiences of people in need of abortion care.[7–12] As these smaller, primarily retrospective collaborations moved forward and our partnerships deepened, we began to think bigger. In 2018, we came together as a research organisation and three activist accompaniment groups to co-design a study to definitively evaluate self-managed abortion with accompaniment support: the Studying Accompaniment Feasibility and Effectiveness (SAFE) study.[5] The aim of this study would be to systematically evaluate the effectiveness of self-managed medical abortion in a larger, prospective, multi-national context.

While science is the primary motivator for those of us that are researchers, and principles of feminism, bodily autonomy, and reproductive freedom motivate those of us that are activists, we share the same goal of generating rigorously collected, prospective data on the experiences of people self-managing medical abortion with accompaniment support and the effectiveness and safety of the model. Each of us, from our own perspective, appreciates the implications these data could have for expanding our scientific understanding of medical abortion experiences, providing more knowledge to people seeking to self-manage, and informing advocacy efforts geared toward the decriminalisation of abortion (and self-managed abortion) and the de-medicalisation of abortion.

From a research perspective, a rapidly growing body of evidence – primarily retrospective in nature – on self-managed abortion has demonstrated the safety and effectiveness of self-managed abortion with medications (misoprostol alone or in combination with mifepristone) in a range of settings and models of information, support, and care.[1] However, prospective data on self-managed abortion were harder to come by, no statistical comparison to the effectiveness of clinician-managed abortion had been conducted, and safety and effectiveness outcomes of self-managed abortion supported by the accompaniment model had not been widely documented.[5] Indeed, a research agenda developed by a multidisciplinary team of researchers identified the

rigorous evaluation of the effectiveness of self-managed medical abortion as one of three priority research gaps,[13] specifically identifying participant recruitment and participant follow-up over time as key challenges that research on self-managed abortion needed to address.

From our decade of collaboration with individual accompaniment groups, we knew that by partnering on a research study across not just one but multiple accompaniment groups in varied country contexts, we could overcome these challenges. Accompaniment groups work with people self-managing their abortions on a daily basis, and thereby can facilitate access to the target population for the study. Further, because the abortion accompaniment model is rooted in trust and open communication, we knew from our previous collaborations that this would translate into an effective model of recruiting and successfully retaining study participants.

From the activist perspective, we have each spent years if not decades advocating for policy change in our countries. We have seen the weight that scientific data can carry in policy discussions, and thus are willing and eager to partner with researchers in the pursuit of collecting high-quality, rigorous data that can inform our advocacy efforts. Our curiosity overcame our politics, and motivated our adherence to the scientific process despite our strong hypotheses about the safety and effectiveness of self-managed abortion. We were further motivated to participate, knowing that our participation could ensure that the research was grounded in the embodied experiences of accompaniers, and the people we serve, around the world – that the research would resonate with the communities we work with, would validate and empower their experiences, and grant them a sense of agency, rather than the sense of extraction that has historically characterised much biomedical research.

These acknowledgments of our shared desire to formally document the effectiveness and safety of self-managed abortion, and the complementary skills and insights that we could each bring to the work, inspired our larger, multi-national, prospective collaboration on this study.

A new collaboration: structure and process

In early 2018, we formalised our mutual interest in collaborating to co-design a study with a research proposal to a funder. This proposal focused on the scientific aims of the study, as well as on the aim of fostering and deepening the principled partnerships between each of our organisations, and the mutual learnings that could ensue.

An overall three-year timeline was essential to our study proposal. While we have worked together on research in the past in individual one-on-one partnerships, this was the first time that we had sought to form a research partnership across multiple accompaniment organisations across varied socio-political contexts to collect data prospectively at a much larger scale than previously undertaken. We devoted the entire first year of the collaboration to strengthening our partnerships, approaching the research process grounded in principles of justice, equity, and shared power and decision-making, and co-designing the high-level structure of the study. As part of this process, we reviewed guidelines for incorporating justice in our work, with the aim of sharing power, and promoting transparency and mutual learning. In this essential first year, we focused on ensuring that the study design was of the highest scientific standards, designed to elicit high-quality data, while also imbued with the activist knowledge and sensitivity to what the self-managed medical abortion experience actually entails in each of the three sites, and anticipating and avoiding any research participation-related burdens to participants.

Designing a study to collect consistent, comparable outcomes across three settings with substantial differences in socio-legal climates related to abortion, and across groups that supported people via different platforms and at varying time points, presented several challenges. Accompaniment partners reviewed the language used in survey questions to help ensure alignment with language used by each group to describe steps of the self-managed abortion process, to avoid response misclassification, and to prevent perpetuation of abortion stigma, among other challenges. Survey questions that felt routine and straightforward for one study site were viewed as invasive and highly sensitive in others, and vice versa. Thought-provoking conversations arose regarding differences in interpretation by country and language of various wording options proposed to measure abortion outcomes, from "complete abortion" to "successful abortion" to "no longer pregnant". Other discussions arose

about if and how pain during abortion is described and discussed across contexts, as well as debate about which participant sociodemographic and reproductive history characteristics were relevant to understanding self-managed abortion experiences, versus which were invasive or unnecessary.

To build understanding and come to consensus on these and other study design issues, a key strategy was to meet in person over several days of meetings to finalise study instruments, to learn more about each other's contexts, and to maximise consistency across sites while maintaining respect and dignity for all participants. As a result, for several survey questions not tied to the primary study outcomes, we came to a compromise whereby questions would not be asked at one or two of the sites to respect country-specific norms of privacy. An additional strategy to overcoming the challenges inherent to this multi-country, cross-disciplinary collaboration included conducting a 60-day pilot[14] in all three sites to evaluate recruitment processes, assess limitations of study instruments, and identify areas for further improvement for the full study. This essential pilot process allowed us to evaluate how well our hopes for study flow and acceptability played out in reality, and to make adjustments accordingly. A central lesson of the pilot study included the need to switch from one particular online platform for data collection to another. The choice of data collection platform for the pilot study was based on finding a platform that was already familiar to and used by the accompaniment group partners; however, due to limited functionality of the platform for prospective research purposes, we made a united team decision to switch to a separate, explicitly research-oriented platform for data collection in the full study.

Finally, as we moved into the second year of the project, we focused on recruitment and data collection from over 1300 participants across three sites; and in the third and final year, we focused our energies toward analysis and dissemination.[5]

A new collaboration: learnings

Each of us, researcher and activist alike, has learned much from this collaboration. Those of us who are activists have gained concrete training in rigorous research methods and research ethics, as well as deep exposure to the meticulous systems required for careful, systematic management of sensitive data over time. These skills and experiences will be essential in building our organisational capacities and tracking the impact of our accompaniment support services over time, and protecting the data that we currently have. Those of us who are researchers have gained insight into alternative views of the biomedical model of care, the expanded range of circumstances in which medical abortion can be and is used, and the staggering bravery and love that our colleagues bring to the radical work that they do in the service of saving people's lives. Our collaboration has also highlighted and framed in a new light the disproportionate elevation of scientific learnings over other complementary learnings from historical traditions, embodied knowledge, and emotional knowledge – knowledge gained by thousands if not millions of people throughout history to provide support and care to people who need abortion. Together, as researchers and activists, our diverse perspectives have helped us to appreciate the role that research can play in empowering people with knowledge, and with a sense of agency in their own health care.

This collaboration was not without challenges. Prospective research with multiple follow-ups and sometimes lengthy surveys is a time intensive endeavour, and necessitated training for accompaniment counsellors, and finding and training a full-time staff person at each site dedicated to research activities. Given the sensitive nature of the study's focus, this required identifying individuals that could be trusted to protect the confidentiality of all participants and accompaniers. Further, given unreliable internet connectivity across some sites, we had to engineer a two-tiered system of data collection that relied on paper surveys filled out by the study coordinator, and then entered into a secure online system when connectivity allowed. As a result, we had to design detailed systems to ensure safe, systematic storage and easy retrieval of all hard copies of study data within each site. To ensure consistency across sites, this required travel by the study PI and additional researchers to each study site to support the implementation of secure data storage policies within each specific office set-up.

Beyond data collection and storage, we also navigated challenges with regard to dissemination. As a study team that operated across multiple primary languages, team calls had to be

structured to include time and energy for real-time interpretation, and similarly, all written dissemination products required time and funds for multiple rounds of translation. On a geopolitical level, during the course of the study, some of us celebrated leaps forward in progress on abortion rights in our countries, while for others, we had to continue to navigate tenuous legal and political environments that often put our work at risk and meant being cautious in our dissemination.

Key to meeting these challenges has been: regular open communication and trust between all partners fostered by intentional in-person time to build relationships and learn about each other's contexts, as well as adequate funding to cover the time of each partner so engaging in research work.

Beyond process, our findings from this collaborative study demonstrated that self-managed abortion with accompaniment group support is highly effective, and comparable to clinician-managed medical abortion.[5,14] This confirmed what we hypothesised to be true, since there is no pharmodynamic reason for the misoprostol and mifepristone drugs to function differently based on where a person takes them – whether seated on a clinic bed, or at the kitchen table at home.

As researchers and activists, we hold that the study results will have far-reaching impact, impact that is magnified because of our collaboration and the wider reach that it entails. Study data offer medical abortion users more detailed information about what to expect from a medical abortion experience in terms of experience of bleeding and cramping, pain management, and side effects.[5] Further, these data strengthen arguments about the power of these medications in the hands of those who need them, lending weight to political conversations about the de-medicalisation of abortion.[5] Importantly, these findings challenge assumptions about the relative effectiveness of misoprostol alone as compared to the combined regimen, and underscore calls for expanded access to and awareness of misoprostol alone as a safe, effective method of abortion care. In terms of service provision, study data point to ways for accompaniment groups to improve the entire experience of care for people whom we support through the medical abortion process, and the data also highlight how much the medical establishment can learn from accompaniment groups about what it means to provide high-quality, person-centred abortion care – care that can be empowering and loving, rather than stigmatising and isolating.

For researchers considering pursuing collaboration with accompaniment groups, and for accompaniment groups considering a new research partnership, the most important learning we can emphasise is the essential need to ground the partnership in a shared articulation and understanding of goals and values. In concrete terms, for researchers, we encourage you to build in time and funds to your project grants to support early in-person time for the full team, timelines that account for multiple rounds of study protocol and instrument review, and time and funds to implement a comprehensive pilot study. Transparent systems and communication agreements should be developed to ensure shared power and decision-making on all relevant areas of study design and implementation, including clear agreements around dissemination activities and audiences. To minimise security and criminalisation concerns, the discussion should cover whether and when it is appropriate to use activist partners' individual and organisation names and locations in dissemination activities. For accompaniment collectives, we encourage clear establishment of confidentiality needs and boundaries, detailed and realistic planning for costs, and for staff/volunteer capacity and interest to engage in research and potential implications on counselling activities and bandwidth, and whether there are opportunities to support and involve accompaniers interested in pursuing research careers.

A new collaboration: concluding thoughts

Over years of close collaboration, we have each come to appreciate that there may always be some aspect of the immeasurable when it comes to abortion. Abortion is inextricably linked to fundamental questions of what it means to be human, of life and death, of autonomy, of liberation and joy. The decision to have an abortion is a decision rooted in compassion, in love, in self-worth, in a belief, and optimism for the future. The infinite ways in which the totality of that decision can play out in people's lives are yes, potentially immeasurable, but perhaps the most consequential thing any of us can do is to commit to listen, to witness, and to support without judgement.

The public health evidence overwhelming concludes that abortion is safe, effective, and essential.[15] Much like the unique researcher-activist collaboration we forged for the SAFE study, the future for abortion access requires the creation of new, expansive alliances across disciplines, philosophies, and silos to provoke necessary, though tectonic, shifts in norms, policy, and practice.

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