

BOLD IDEAS: PLANNING FOR CARE
Lecture in Honour of Pat Kaufert given by Pat Armstrong at the University of
Manitoba, Sept. 17, 2021

Pat Kaufert received her Ph.D. in 1976 from the Centre of West African Studies at the University of Birmingham, England. Coming to Canada in 1977 she was awarded a post-doctoral fellowship to retrain as a health researcher specializing in the fields of medical sociology and medical anthropology. A Professor in the Department of Community Health Sciences in the Faculty of Medicine at the University of Manitoba, she was a pioneer in women's health research and an outstanding, quiet activist within and without the university. She died in 2019 and a Lecture series was established in her Honour. This is the first lecture in that series.

It was truly humbling to be asked to give an inaugural lecture in honour of Pat Kaufert and to do so by talking about my own work. I thought one way to honour her is to review some of our collective success in women's health while cautioning how fragile these successes are.

Those of us in the women's health movement have been asking and answering four central questions for decades, combining evidence and action, with one informing the other. Why is this a women's issue? What are the issues for women? For which women? And a question that was central to Pat Kaufert's work, what can we together do about it? To illustrate, I want to explore the examples of birth control, maternity care, health care services and long-term care -all areas of bold ideas where Pat played a critical role.

Let me begin with the Montreal Health Press, started by a group of McGill students. In 1968, when it was still illegal to provide information on or access to birth control, they published the first Birth Control Handbook. In addition to providing accessible, free information, the handbook undoubtedly played a part in support for the 1969 legalization of contraception and inspired the US publication *Our Bodies. Ourselves*. By 1974, the Press had distributed 3 million free copies via health & educational organizations. Three similar publications followed: one on STDs, one on sexual assault and one on menopause. It may seem obvious that these were women's issues, but I well remember that when the girls in my high school demanded we see the VD film shown to the boys, we failed.

The books clearly established these as women's issues and issues for all women—albeit in different ways. They identified what the issues are and did so with

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methods that provided evidence-informed tools for transformative change, including self-care.

The picture of their 1983 meeting could well be any women's group doing the work and symbolizes the voluntary labour combined with other care work that is so central to feminist process. Judith Crawley, MHP photo editor as of 1980, contributed many of the Handbooks' pictures, commonly taken from her daily life.

The original birth control handbook had some funding from the McGill student council for printing, and the group later had some financial support from both the Quebec and federal governments. The rest of the direct costs were covered by organizations that paid a dollar for each handbook and promised to distribute them free. I raise this because funding was and is both essential to getting the work done, even when so much of it is unpaid, and essential to recognizing this as necessary work. Equally important, it meant the information was free.

As Donna Cherniak, an original member of the Press and now a physician, said in preparation of the University of Ottawa's Women's archives' virtual exhibit about the handbookⁱ, the approach:

has to do with going beyond the medical model...

One of the slogans of feminism was, and still is 'the personal is political'.

The medical model taught about plumbing: anatomy, physiology. etc.

The book does that but also puts contraception/sexuality in the domain of human relationships--issues of consent, agreeing to use contraception (or protection from infection). And these negotiations are done by people who have been influenced not only by their personal experiences, but by the socio-political environment in which they live. Gender roles, expectations about sexuality for men and for women, financial issues, religion.

This challenging of the medical model and the inequities embedded in it could well have been a quote from Pat Kaufert, especially as it relates to maternity care. I am reminded of her article titled *Cooptation and Control: The Reconstruction of Inuit birth*. It is research that employs rigorous methods but makes no pretense of being objective or simply descriptive in the sense of being without values,

recognizing that all research starts with assumptions embedded in values but what is critical is to make those values explicit.

The women's health movement supported by research such as Pat's, has been primary in transforming maternity care, moving it away from a medical model. Obviously, a woman's issue, the issues for women were not so obvious. Hard to believe now that shaving and enemas were the common practice, as were anesthetics and the exclusion of fathers. I not only experienced all that but was rolled into an operating theatre to be an exhibit for medical students, without my consent. I kept hoping none were my students. Breast feeding in public was also not allowed, with one famous case of a woman forced to breast feed her baby in the airplane washroom.

Of course, the women's health movement was also central to legalizing midwifery. As Ivy Bourgeault shows in her book *Push. The Struggle for Midwifery in Ontario*, midwives, like the students at McGill, had been operating outside the law while working for change. They were eventually successful in demanding the decriminalization of midwifery and in getting public funding, as well as in establishing a university program that was independent from medicine and that required a women's studies course. Moreover, it included a program for Indigenous midwives, addressing the question of which women. We were asked by the Ontario Interim Council on Midwifery to advise on how the new program should evaluate students and midwives from other countries. Having learned from and with the women's movement, we said we would only do so in partnership with these who had been doing midwifery work. It was certainly an education, not only in midwifery and collective action but also in the importance of combining evidence with action and in recognizing multiple ways of gaining knowledge. Together we struggled through how to assess skills in ways that explicitly recognized the importance of woman centred care that address differences among women. Interviews, approaches, and practice assessment were prioritized, not multiple-choice exams.

My third example of collective work is a group we called women and health care reform. Thanks to pressure from the women's movement, there was stable funding then through the federal Women's Health Strategy, established in 1996. We came together in 1998, with representatives from the Centres of Excellence for Women's Health including Margaret Haworth-Brockman, Ann Pederson, Barb

Clow and Karen Grant, and Madeline Boscoe from the Canadian Women's Health Network. Our mandate was to identify and fill gaps in the research and, equally important, translate research into policy and practices. With that funding came the freedom to identify and define critical issues as well as share what we learned with both communities and governments. We used every avenue we knew, as Pat did, presenting to Standing Committees, community groups and conferences.

One of our early efforts was a workshop on unpaid care and homecare. It became our model. One third of the participants were researchers, one third were those who provided care and one third were policy makers, based on the understanding that all had expertise to contribute. Participants were provided with background research to allow us to have a shared basis for discussion that provide common ground to move forward in our work together. It began with a public panel to set the stage and share beyond this group. Very quickly, the collective decided they didn't want to sit around planning more research but rather to build on what we know to set out what is to be done, based on what principles. The result was the 2001 *Charlottetown Declaration the Right to Care*. Those of you who know your Canadian history will get the play on that 1864 meeting of white men to plan Canada.

It began:

Canadian society has a collective responsibility to ensure universal entitlement to public care throughout life without discrimination as to gender, ability, age, physical location, sexual orientation, socioeconomic and family status or ethno-cultural origin. The right to care is a fundamental human right.

It went on to specify these rights. Perhaps most startling is the right not to care. We think unpaid care should not be compulsory, as it is for so many women when services and supports are not available and when there is so little recognition of the skill, effort and responsibility involved. Universality is the starting point but asking not only about women's issues and which women takes us to another set of principles, as the document goes on to explainⁱⁱ.

This was just the beginning of a workshops series, each addressing a different area of health services and each of which resulted in what we called our popular

pieces. Like the McGill students, these were written in accessible language, included photos and cartoons, and were distributed for free in paper or electronic form. Thousands were downloaded and organizations such as the Pan-American Health Organization asked to copy the format.

Some topics, like homecare, maternity care and primary care, were more obviously health services and more obviously about women. But there were less obvious ones, like the one on women and disasters that exposed how women, and particular groups of women, face specific kinds of risks and provide specific kinds of work during emergencies, much of it invisible. Compare this to the commemoration of 9/11 that focused primarily on firefighters, and guess who mainly does that.

Madeline's elevator encounter with Dr. Brian Postl, who was then writing a report for the federal government on wait times, led to our research on gender and wait times being included in his report, albeit as an appendix. Wait times illustrates another important lesson from this group. Because we worked together for over a decade, and because we had funding to meet as a group, we could respond quickly to policy developments. For example, we did a press release the day the Romanow report on the future of health care was released. It was followed within a week by our *Reading Romanow* piece, that exposed the lack of a gender analysis not only in failing to address women as patients and providers but also in dismissing traditional women's labour in what was described as ancillary work in food, laundry and housekeeping.

We also did a popular piece on evidence, another area central to Pat's work, especially around menopause. We asked how gender and other social relations matter in what counts as evidence and whose evidence counts, providing critical ways of reading research. Many of us involved in the women's health's strategy, like Karen Grant and Lorraine Greaves, were at the same time heavily involved in pushing for an institute in CIHR that would focus on women. Within CIHR, we worked to have a wider range of evidence recognized as legitimate science and to require explicit statements about how gender was taken into account.

After more than a decade working together, we closed when the Harper government first said our workplan would have to show how it supported their platform and then ended the funding entirely.

One of our last workshops was on long-term care, resulting in a small book titled *A Place to Call Home*. Perhaps not surprisingly given these times, it is being read more now than when it was released in 2009.

I was first drawn into studying long-term care by my work around pay equity and the blatant undervaluing of women's work. As I am sure you know, long-term care is primarily about care for women by women, many of whom are newcomers and/or racialized. Much of the work is seen as unskilled work any woman can do by virtue of being a woman, and thus as requiring little formal training and deserving few financial rewards. And of course, it is about the value we put on old women, as Pat so eloquently made clear in her work on menopause.

Our comparative research with Nordic countries had revealed alarming rates of violence against workers, with Canadians six times more likely than their Nordic counterparts to say they faced violence daily. It was women who experienced this, not only because they provide the majority of care but also because as women, they were often blamed for the violence they experienced. Prompted by this, we successfully applied for a large international, interdisciplinary study to reimagine long-term care. It brought academics and students who had multiple ways of seeing together with our union, community, and employer partners to do research that explicitly created a dialogue between theory and evidence as well as among various groups, as Pat so effectively did.

Our methods are feminist in at least five ways. First, the research process is collective as well as democratic, with data and ideas constantly shared and challenged not only within the team but also outside it.

Second, we focus on listening to and observing those who live, work, manage and visit in nursing homes. This was particularly evident in our primary data collection through what we call rapid, site switching team ethnography. 12 or 14 of us went into at least 2 homes in each of the 6 countries, working in teams and in shifts from at least 7 am until midnight. We constantly consulted with, challenged, and supported each other while we conducted this intense research, as we explain in our book *Creative Teamwork*.

Third, we take gender, as well as its intersection with other social relations, as central to the analysis, recognizing inequities in power, and resources, as well as in bodies and histories.

Fourth, we struggle to make the invisible visible, especially when it comes to women's work and to the structural violence, as Paul Farmer names it in his book *The Pathology of Power*. Our approach means attending to unpaid work of families, volunteers and those otherwise paid to do the work, it's relationship to paid labour and the skills involved in both, as well as to the structures that shape the work and care experiences in unequal ways. In doing so, we demonstrate as we have in the past that the conditions of work are the conditions of care.

Fifth, in keeping with so much of the feminist literature, we understand care as a relationship and all of the work as skilled. This leads us to challenge medicalization, as the McGill students and Pat did, stressing the importance of both social and critical care, and of food, clothing, laundry, and housekeeping as central to care and to the joy that Atul Gwande calls for in his book *Being Mortal*.

Our book *Wash, Wear and Care* makes this point using clothes and laundry. When we asked about clothes and laundry in a meeting we had in Winnipeg with the Board of a care home, the chair dismissed the issue. However, the two women family members on the board immediately challenged him, easily recognizing how important cloths and laundry are to dignity and respect, as well as to safety.

In our comparisons we are seeking promising rather than single, best practices, because we understand that contexts and populations matter even though there are some very clear lessons, like don't contract out food services and do ensure enough staff. Building on so much of what the women's health movement has taught us, we have worked to make evidence-informed knowledge accessible. Our four small books from the Reimagine project are available in paper or electronically without cost and have been snatched up in the thousands. They provide concrete examples from different countries of promising practices. Of course, we have also produced more traditional kinds of academic publications, based on the multiple methods we have employed, establishing the peer-reviewed basis for our work.

As is often case with the social sciences, in our more than a decade of work it was often hard to show any concrete impact besides citations! But as is also often the case, the research has suddenly come into its own. Unfortunately, it has taken the pandemic but now even the Prime Minister is saying that the conditions of work are the conditions of care.

In conclusion, there are at least two ways of seeing these four examples of birth control, maternity care, health care services, and long-term care. We have certainly made progress together, as Pat Kaufert's work encouraged us to do.

We have made significant gains in access in access to birth control and to midwifery. We have altered maternity care, we have demonstrated that there are women's issues in health services related to everything from wait lists to unpaid care work and we have contributed to the improvement of wages for those who provide care. We have expanded what is defined as evidence and whose evidence counts, demonstrating that gender and other social relations of inequity always matter. And we have acquired some funding that recognizes the importance of this work, effectively using this funding to create and share evidence.

We have done so by combining research and action, with each informing the other, working with unions and community groups learning with and from them. And we have done so by putting evidence in women's hands.

But there is another way of seeing where we are now. Many of our gains are fragile, stalled or under attack. Access to abortion is under threat in the United States. This threat may trickle up here and may well be accompanied by other limits on women's bodies. Sexual assault is being reported in growing numbers on campuses and our progress on menopause has stalled.

The women's health movement fought successfully to de-medicalize birth but for some, especially homeless women or women from brutal homes, this can mean only one day with hospital support. In some provinces and territories midwifery is not yet funded or regulated. In Ontario, the only program for Indigenous midwives is under threat as Laurentian University is decimated. In a pay equity case for midwives in this province, the Government is appealing the Human Rights Commission decision that found in the midwives' favour. This Government has also passed wage restraint legislation that applies to nurses and teachers but not

to firefighters and police officers. And, under pressure, Alberta seems to have backed off the most obvious cuts to nurses' wages but instead using less obvious processes to mean reductions.

We no longer have the Women's Health Program and with the Institute of Gender and Health it seems like more of the money is going to men's health and to more traditional forms of medical research, albeit with assurances that gender will be taken into account. Today there is lots of misinformation out there and we no longer have Canadian Women's Health Network to help us sort it out.

The conditions in long-term care have been exposed but I wonder how far we have come or plan to go when the moderator in the election debate asked; "Would you put your mother in a home"?

I give these examples of setbacks, contradictions and even failures not to depress you or to suggest that we have not made significant progress in understanding and addressing women's health, because we have. Moreover, struggles to improve women's health have certainly not disappeared and I see very important signs of collective, evidence-informed action to transform long-term care.

Rather I have rehearsed these limitations as a call to action, learning from our past. Indeed, I do so as a celebration of both Pat Kaufert and of our work together, work that continues informed by her legacy. Women's work is never done which is why we have to make sure we have fun doing it, as Pat so obviously did.

ⁱ biblio.uottawa.ca/omeka1/arcs-en/exhibits

ⁱⁱ The Charlottetown Declaration on the Right to Care

https://www.cwhn.ca/sites/default/files/PDF/CEWH/health_reform/charlottetownEN.pdf