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Promoting Culturally Accessible, Community-Centered, Midwifery Care in the Rural Anabaptist Population of Southwestern Ontario, Canada

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Abstract: The experience of providing midwifery care in a rural Southwestern Ontario community is discussed, highlighting specific approaches to providing culturally accessible and community-centered care among the Old Order Anabaptists. Midwives in Ontario are primary care providers for perinatal care and the clinic described in this paper works primarily with families from Anabaptist communities. Success in providing culturally accessible care has come from community engagement and responsiveness to ways to improve access to healthcare in this region. Highlighted in this article are the scope of midwifery care in Ontario, home and hospital births, collaboration with other community agencies, and community-based genetic screening. [Abstract by author.]

***Keywords*:** Old Order Mennonites; Amish; Low German Mennonites; rural healthcare; home birth; community-centered healthcare; genetic screenings

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INTRODUCTION

As a Registered Midwife, I have had the opportunity to spend my career working with many families in the plain communities of rural Southwestern Ontario. It has been an honor to be invited into people's homes, to be part of their childbearing care through the antenatal, birth, and postpartum periods. For almost 20 years I have had the privilege of caring for whole families of sisters, mothers, and daughters, and to experience the joys of parents having their first and sometimes their thirteenth baby. It is an honor to be part of moments of joy, and occasionally sorrow, which are part of childbirth. I have strong respect for the mutual aid and support networks within plain communities that assist parents as their families grow. I have learned how internal community support improves outcomes through care of parents during these life experiences.

COUNTRYSIDE MIDWIFERY SERVICES

Countryside Midwifery Services provides care across a large catchment area where many diverse plain communities reside in parts of Perth, Wellington, Huron and Waterloo Counties in Ontario, Canada. Our two main clinic sites are in Milverton (Perth East Township) and Harriston (North Wellington County), Ontario. We have grown from a small solo practice founded over 40 years ago by Midwife Violet Ropp, a member of a local Mennonite church, to a large practice group of 16 midwives. Ontario was the first province in Canada to regulate midwifery services in 1994 as a self-regulated profession under the College of Midwives of Ontario. As midwifery became a regulated profession, Countryside Midwifery Services was one of the founding regulated midwifery practice groups in the province. Our midwives come from a variety of backgrounds. Most are graduates of the Ontario Midwifery Education Program and some are internationally trained midwives from the United Kingdom and the United States. Only a few of our midwives identify as having a Mennonite background.

In our catchment area, we care for families from many Anabaptist groups including: Old Order Amish, Old Order Mennonite, Independent Old Order Mennonite (formerly David Martin Mennonite), Orthodox Mennonite, and Low German Mennonite, as well as many Conservative Mennonite and Amish-Mennonite families. The Anabaptists represent over 70% of our clientele, with 30% to 40% being from horse-and-buggy groups. We provide care to the full community, with many 'English' clientele as well.

MIDWIFERY CARE IN ONTARIO

Growth of midwifery services in our practice group has been strongly linked to integration and funding of midwifery care across the province following regulation of midwifery. We are seeing the largest areas of demand for services linked to population growth of many people moving from the urban regions of Kitchener-Waterloo (affordable housing, suburban expansion), rapid population growth within the Old Orders with larger family sizes, and a growing demand for midwifery care across the province.

In Ontario, midwives are primary care providers for the entirety of pregnancy, birth, and postpartum period, up to 6 to 8 weeks after the birth. A physician is only consulted if high risk conditions present. Midwives order laboratory tests and ultrasounds related to pregnancy and are able to prescribe medications for common prenatal and infant concerns. People seeking care contact our group directly and do not need a referral.

Each province and territory in Canada has its own structure for regulation, payment and support of midwifery services. In Ontario, we bill directly to the Ministry of Health and Long-Term Care for the services we provide, regardless of insured or self-pay status. Our funding system allows us to be paid to care for uninsured residents of Ontario, including new immigrants, refugees, and migrant worker families (often Low German Mennonite families). Hospital fees are still billed to uninsured inpatients, although the actual delivery under a midwife in hospital is covered. We strive to offer payment options that respect the cultural choices of our Anabaptist communities. Although the majority of our Old Orders choose to have uninsured (self-pay) status, there are some local Old Order groups that choose to participate in the provincial Ontario Health Insurance Plan (OHIP). For Anabaptists who choose to remain self-pay, we do not require or solicit payment. We encourage families who wish to pay to consider making a donation to their church or to a community fund

in lieu of payment to us. If they prefer, there is a provision in our funding system to allow them to "opt-in" to pay us directly as well. We declare their payment when billing for services, and we do not receive government funding for their care.

MIDWIFERY MODEL AND CHOICE OF BIRTHPLACE

We offer the options of home birth, clinic birth, and hospital birth in our practice. We have a home birth rate of approximately 40%, and slightly higher in our Old Order communities. Birthing at home in Ontario for low-risk women with a registered midwife is supported as safe, showing comparable outcomes to hospital births, with a reduction in interventions (Hutton 2016; Hutton, et al. 2016). We attend all home births with two healthcare providers present for the delivery. We offer options for birthing in water (with adaptations available for homes without electricity) and carry equipment, medications, and oxygen to manage emergencies at home if needed. We have a good relationship with paramedical services. If transport to the hospital is needed, we continue to provide supportive care in person at the hospital as an integral part of the care team.

Many of our clients opt to deliver in one of our local hospitals where we hold admitting privileges. Reasons for choosing a hospital delivery vary widely: a higher risk pregnancy, medical options for pain relief, and the inconvenience of a home birth when there is a large family. With an uncomplicated vaginal delivery, midwifery clients may not even meet a nurse or physician during their stay in the hospital. When birthing with two midwives in attendance, many families opt for an early discharge, reducing inpatient fees for self-pay clients. For women who are higher risk, and require care from a physician, midwives still attend their labour and birth as a part of the care team, offering labour support and advocacy for choices.

Following delivery at home or in the hospital, we continue to care for clients for 6 to 8 weeks. We complete newborn screening, including for heart defects and jaundice, in clients' homes. We offer breast-feeding support and conduct well baby care including weight checks at home.

As primary healthcare providers, we are able to offer medical (prescription) and natural treatments for pregnancy, labour, and postpartum, with a broad choice of options. Our Old Order community members often prefer herbal or "natural" approaches as the first line of treatment. Our midwives support choices for alternative health and coordinate with alternative health providers such as naturopaths, chiropractors, and craniosacral therapy. We offer non-medical approaches to pregnancy, labour and birth, including natural methods of induction of labour and non-pharmacologic options for pain management of labour. In the hospital, we are able to offer clients pharmacologic options for pain relief, including epidural in coordination with our medical colleagues.

COMMUNITY-CENTERED CARE

Community-centred care requires consideration of cultural accessibility of health services. This encompasses physical accessibility, language/interpretation resources, education for healthcare providers about cultural communities, as well as the way care is provided with an approach that is adaptive to individual clients and communities. This approach is used in our midwifery clinic while working with the Anabaptist population.

Our practice group strives to improve access to midwifery care in the rural population we care for, with particular attention to healthcare access for the Anabaptist population. Nussey, et al. (2020) described the concept of community-centred care as having "established or evolved their practice into an integrated and reflexive part of the community they serve" (p. 33). As a healthcare group, we consider access to healthcare both a practical endeavour, looking at physical accessibility, and a commitment to cultural accessibility.

Some of the practical approaches to physical accessibility include: home visiting, funding interpreter services, and investing in equipment to offer care outside of hospital for fetal monitoring and ultrasound. The Anabaptist settlements in Southwestern Ontario are large regions, with larger sized farms spread further apart than would be typical in Amish settlements in Ohio and Pennsylvania. Visiting the clinic may require 10 to 120 minutes travel time by horse each way. Thus, we offer care at home for horse-and-buggy and 'English' clients who lack access to transportation for the entirety of prenatal, birth, and postpartum

care. To reduce travel and appointments, we obtain laboratory specimens for clients in their homes or in our clinic. The majority of our midwives have done training in the limited use of ultrasound that can be performed in client homes to assess fetal viability and fetal position.

Cultural accessibility is a nuanced, multi-faceted approach to providing respectful care. A primary focus is ongoing education for midwives and staff to understand the cultural communities we work with as well as best approaches in offering care. Ongoing education includes orientation of new midwives to our cultural groups through written materials developed by our local health community, with feedback from Anabaptist leaders and community members (Perth District Health Unit [PDHU] 2012).

We have adopted job-shadowing as part of orientation of new staff. This includes informal orientation offered by midwives to new staff as well as a formal partnership with Huron Perth Public Health Unit. We recognize consistency of staff is very important to our cultural groups and introducing new staff by members "already well-known and trusted by members of the Anabaptist communities" (Perth District Health Unit (PDHU) 2012, 61) helps to integrate them into the community. Through this partnership with Public Health, new midwives can do an observational placement with experienced nurses working primarily with the Anabaptist groups. Similarly, we offer an observational placement for new nursing staff to job-shadow an experienced midwife.

Cultural accessibility requires optimal communication delivered in a manner that is responsive to our cultural groups. It is recommended that healthcare providers working with the Anabaptist community "adapt a low-key, humble, non-threatening and non-aggressive approach with their clients…dressing modestly and respectfully" (PDHU 2012, 61), especially when providing care in the home environment.

Since our Old Order groups rarely access formal prenatal education, we dedicate extra time to providing it during home visits. A sharing library of materials is brought out to home visits. For clients from the Low German Mennonite community, we fund interpretation for appointments and dedicate longer visit times to ensure good communication.

We actively collaborate with other service providers to foster culturally appropriate care in our rural communities, including Public Health, our local community hospitals, family physicians, and nurse practitioners. Public Health nurses provide home visiting well-baby checks after clients are discharged from midwifery care, nutritional/dietician services, and host education events such as pressure canning workshops and farm safety events. We work with new medical and midwifery trainees to develop increased knowledge of the community and best practices for culturally appropriate care. Our local family physicians have supported the development of a very successful Maternal and Young Child Clinic for the Anabaptist communities led by a nurse practitioner. We shared clinic space and resources to help this program grow.

COMMUNITY GENETICS SCREENING PROGRAMS

The local Old Order Anabaptist populations have a higher incidence of some rare genetic conditions affecting infant and childhood morbidity and mortality (Payne, et al. 2011) so we offer local testing and counselling related to community-based genetics with the support of the Medical Genetics Department at the London Health Sciences Centre (London, Ontario). With support from geneticist Dr. Victoria Siu, and Dr. Anthony Rupar, and Public Health, we have developed a coordinated approach to community genetics screening offered at home by midwives. We offer genetic screening for couples from the Old Order Mennonite and Old Order Amish, as well as infant cord blood testing for at-risk families, to ensure timely diagnosis of rare conditions. This work has improved care by decreasing morbidity and fatal outcomes for many infants in our communities. These genetic screening programs have been developed with the support of and in coordination with local church leaders.

The community genetics screening programs have evolved over time to respond to community needs and requests for expanded services (Soulliere, et al. 2021). This started as a pilot project in 2003 with collaboration between Drs. Sui and Rupar at LHSC, PDHU (now Huron Perth Public Health) and Countryside Midwifery Services. The initial project involved offering cord

blood screening at birth for all Amish newborns for four known treatable disorders seen in the local population: cystinosis, congenital glaucoma, cystic fibrosis, and galactosemia. In consultation with the church leaders, a choice to report affected status only was adopted. Carrier status only is not disclosed. This program was highly successful and well over 95% of families participated in it.

The community genetics screening program gradually expanded with an increase in genetics knowledge and testing options. Although only affected status was reported, the testing process created knowledge about the frequency of carrier rates for these conditions. The frequency was higher than expected and this information was shared amongst local healthcare providers and community leaders and members. At the same time, testing for new disorders became possible through identification of the genes responsible for some conditions. These include Fraser syndrome, congenital sodium diarrhea, and HARS (formerly known as Sudden Infant Death). All of this led us towards the next step; genetic testing of married couples to identify hereditary conditions prior to birth as a way to optimize outcomes for affected infants.

The major catalyst to this change was an event that occurred in our community, where a family had an infant diagnosed on day 5 of life with galactosemia. Galactosemia is a metabolic condition where damage to the brain and liver occurs when an affected infant is fed human breast milk or animal-milk based formula. At the time of diagnosis, this infant had already been admitted to our local hospital with weight loss of over 12% and worsening jaundice that developed into liver failure. Galactosemia was part of the Ontario newborn screening program at that time, and results came back as the infant was transferred to the tertiary care unit in critical condition. This baby recovered well once the diagnosis was confirmed and appropriate treatment initiated. Given the high carrier rates in the plain population, it became clear that optimal care would mean knowing which infants were at risk prior to birth to avoid severe outcomes such as this.

Community screening of Amish married couples was initiated as another joint initiative between health partners and the local community leaders. Support from the community happened quickly as families and church leaders responded to the event described above. The success of the Amish cord blood screening program built trust and connections between the community and genetics specialists. The program is offered as an optional test to couples by midwives and other local healthcare providers, with testing in the community eliminating travel to London (1 to 2 hours by car). There is now a panel of known genetic disorders in the Ontario Amish communities, testing for over 15 conditions. This program was adopted very successfully, with over 90 to 95% or couples screened for carrier status prenatally. Those that opt out of the carrier status screening participate in the Amish cord blood screening program.

The success of this initiative has been evident in the improved health outcomes we see as midwives in our care of families. For parents who are both carriers for galactosemia, cord blood testing is conducted at birth and sent immediately to LHSC for assessment. Infants are restricted from exposure to human or animal milk proteins until diagnosis can be made. If the child is unaffected, resumption of nursing occurs immediately. Often this process can happen within 10 to 24 hours of birth and is offered to families birthing at home or hospital. Similarly, this has accelerated diagnosis of other treatable disorders in the panel – connecting infants and families with specialist care prior to symptom onset.

The success of this program has led to the development of a similar screening program for rare genetic disorders among Old Order Mennonite married couples in Ontario. Keys reasons for the overall success of these programs and their continued development are: local connections with church leaders at times of development and change, connection with midwives as trusted local healthcare providers, and responsiveness to community needs and easy methods of communication between specialists, families and local care providers.

CONCLUSION

The work of midwives at Countryside Midwifery Services has evolved in response to community requests and preferences to provide care that is both culturally accessible and community-centered. We have made our Anabaptist communities central to our program's development and offer options to improve access to healthcare

services in a vibrant rural population. Central to this is care at home, both for prenatal and postpartum clinical visits as well as offering choices for birthplace, including home birth with skilled healthcare professionals. Collaboration with other service providers has improved access to healthcare for the Anabaptist community, exemplified by our community genetics screening program, offering options for this service locally by midwives known as culturally sensitive care providers.

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