

Postpartum women living with HIV: Challenges related to retention in care, treatment adherence, and mental health

Questions

- What are the challenges related to retention in HIV care during the postpartum period?
- What are the challenges related to HIV treatment adherence during the postpartum period?
- What are the challenges related to postpartum depression among women living with HIV?
- What effective interventions or promising practices can be used to support women with the above issues (particularly interventions by social workers, community workers and peers)?

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Key Take-Home Messages

- Postpartum women living with HIV may find it challenging to remain engaged in HIV care and achieve optimal adherence to antiretroviral medications (1, 2).
- Late entry or suboptimal engagement in care prior to delivery is associated with poor engagement in care in the postpartum period (3-6).
- Some studies have identified that adherence to antiretroviral therapy can decrease during the postpartum period (7-9). One systematic review found that only about 74% of postpartum women living with HIV achieve optimal adherence to antiretroviral therapy (10).
- Psychiatric symptoms, particularly depression, can impact well-being, quality of life, and other important clinical outcomes among pregnant and postpartum women living with HIV (11).
- The Perinatal Case Management intervention, designed specifically for pre- and postpartum women living with HIV, improved retention in HIV care and antiretroviral adherence outcomes among a U.S. population (2).

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The Issue and Why It's Important

The term postpartum, also known as postnatal or puerperium, refers to the period of time following the birth of a child when the mother's physiology returns to a non-pregnant state (12). The postpartum period is a critical time for both the mother and newborn (1). Effective care during this time can prevent short-, medium-, and long-term consequences for a variety of issues (13).

For women living with HIV, one element of postpartum care involves ongoing HIV care. This should be established prenatally (i.e. between conception and birth) (14). Two elements of ongoing HIV care are retention in care and adherence to antiretroviral medications (15, 16). Staying retained in HIV care allows treatment adherence to be monitored (15, 16) and achieves viral suppression (16). Having a suppressed viral load prevents infection of HIV from mother-tochild during pregnancy and delivery, helps the mother stay healthy, and prevents transmission of HIV to other partners (17). However, some postpartum women living with HIV have suboptimal rates of retention in HIV care (3, 18, 19) and inadequate adherence to antiretroviral therapy (10). Indeed, maintaining retention in care and achieving optimal adherence to medications can be difficult for new mothers (1, 2).

A second concern, not limited to women living with HIV, is postpartum depression. Postpartum depression is a mental illness that impacts how individuals feel about themselves, and can include feeling anxious, sad, worthless, hopeless, or guilty (20). Postpartum depression can be experienced by both the mother and the father, and can begin during pregnancy, or at anytime up to a year after the child's birth (20). One review of over fifty studies found that there is a high prevalence of depression, general distress, and other psychiatric symptoms among pregnant and postpartum women living with HIV (11).

The focus of this review is on postpartum mothers living with HIV in high-income settings, with special attention given to three issues: retention in HIV care, adherence to HIV medications, and mental health. Factors related to these issues are explored and strategies to address these challenges are identified. 6. Swain CA, Smith LC, Nash D, Pulver WP, Lazariu V, Anderson BJ, et al. Postpartum loss to HIV care and HIV viral suppression among previously diagnosed HIV-infected women with a live birth in New York state. PLoS ONE. 2016;11(8):e0160775.

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💷 What We Found

Mother-to-child transmission of HIV

Mother-to-child transmission (MTCT) of HIV, also known as vertical or perinatal transmission, is a critical component of care for the mother and infant during pregnancy, delivery, and the postpartum period (14). While the purpose of this review is not to explore MTCT transmission rates, guidelines, or prevention of MTCT, the prominence of this public health issue among women living with HIV warrants discussion. This section prefaces the challenges faced by postpartum women living with HIV by briefly outlining the current global status of MTCT, the nature of available literature, and our rationale for focusing on high-income economies.

Prevalence of mother-to-child transmission: Canada and globally

Research has shown that the most effective intervention to prevent MTCT of HIV is combination antiretroviral therapy (21–24). The Canadian guidelines for the care of pregnant women living with HIV state that consistent use of antiretroviral therapy, in addition to abstaining from breastfeeding, lower the risk of perinatal transmission to less than 1% (14). While the rate of MTCT in Canada has declined, missed opportunities still occur; between the years of 2011–2016, 14 cases of MTCT were recorded in Canada (25).

Perinatal transmission of HIV varies drastically across the globe. Currently, the WHO African Region carries the largest burden with more than 90% of new HIV infections among children (26). However, significant improvements have been made: from 2009 to 2015, there was a 60% reduction (270,000 to 110,000) in new HIV infections among children in the 21 sub-Saharan African priority countries (27). Nonetheless, critical gaps remain (27–29).

Mother-to-child transmission of HIV in the postpartum period: Infant feeding

In the postpartum period, MTCT of HIV can occur via breast milk (30, 31). The Canadian guidelines state that "[b]reast-feeding is not recommended regardless of plasma HIV viral load and use of antiretroviral therapy" (14); American guidelines also do not recommend breastfeeding (32). However, in light of recent evidence and the proven benefits of breastfeeding, the recommendation to completely abstain from breastfeeding among women living with HIV has been revisited (33, 34). Recent guidelines from the British HIV Association state that "the safest way to feed infants born to mothers with HIV is with formula milk" but that "[women] who are virologically suppressed on cART [combination antiretroviral therapy] with good adherence and who choose to breastfeed may be supported to do so" (35). The European AIDS Clinical Society advises against breastfeeding, but in cases where women insist on breastfeeding, they "recommend follow-up with increased clinical and virological monitoring of both the mother and the infant" (36). 12. Berens P. Overview of postpartum care. Available from https://www.uptodate.com/contents/overview-of-thepostpartum-period-physiology-complications-and-maternal-care Accessed October 16, 2018. 2017.

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Postpartum women living with HIV: Literature and the global context

The literature focusing on prenatal and postpartum women living with HIV in high-income settings is limited (2, 6, 38). Our search of the literature did identify numerous studies and reviews on women living with HIV in the prenatal and postnatal stages of maternal care; however, the majority of these studies were conducted with women in low-income settings (primarily in sub-Saharan Africa) and mainly focused on MTCT of HIV. Several systematic reviews relevant to the research questions were identified (10, 39–44). However, a closer inspection revealed that, despite comprehensive search strategies, authors were only able to identify a few studies from high-income settings.

As discussed above, the rate of new HIV infections among children in sub-Saharan Africa is significantly greater compared to highincome settings, such as Canada. While UNAIDS has set a global target of 90-90-90 for 2020 (i.e. 90% of people living with HIV will be diagnosed; of those, 90% will be on treatment; of those, 90% will be virally suppressed) (45), the factors that drive the epidemic may be significantly different depending on the economic setting (46). These include the extent of diagnoses among those living with HIV, coverage of antiretroviral therapy, access to healthcare services, and surveillance systems that describe the epidemiology of HIV (46). Indeed, not all women have the same opportunities and access to critical resources for HIV care and effective prevention of MTCT (11). Furthermore, the different socioeconomic and cultural landscapes among high- and low-income economies require HIV prevention interventions to be context-sensitive (47). As a result, this review excludes studies conducted in low- and middle-income economies as defined by the World Bank Country and Lending Groups (48) and focuses on issues and interventions specific to postpartum women living with HIV in high-income settings.

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Challenges to HIV care during the postpartum period

Canadian guidelines state that "maternal antiretroviral therapy should be continued after delivery and reassessed for ongoing therapy by providers of adult HIV care" (14). This recommendation reinforces the importance of retention in care and adherence to HIV medications for postpartum women living with HIV. However, there are unique challenges that women living with HIV may encounter that impact their engagement in HIV care and adherence to antiretroviral treatment. The following sections briefly outline the challenges associated with these two aspects of care and identify strategies to address these obstacles.

Postpartum retention in HIV care

Retention in HIV care refers to scheduled visits with a primary HIV care provider, although there is no standard as to how often these should occur, and over what period of time (49). Staying retained in HIV care is an ongoing process critical to maintaining optimal health among all people living with HIV (15). Postpartum women living with HIV face unique challenges that may prevent them from staying retained in HIV care. Studies in high-income settings that identified predictors to poor retention in care are outlined below:

- One study among 980 postpartum women in the state of New York, diagnosed with HIV at least one year before conception, found that poor engagement in HIV care preconception predicted loss-to-follow-up postpartum (6).
- Data from the Swiss HIV Cohort Study (695 pregnancies in 580 women) found that being lost to follow-up was significantly associated with a history of injection drug use and not achieving an undetectable viral load at delivery (50).
- A cohort analysis of women living with HIV in Philadelphia (695 deliveries in 561 women) found that women who engaged in HIV care within 90 days of delivery were more likely to be retained in care and virally suppressed in the first and second year after delivery (3).
- A mixed-methods study conducted among a small sample of low-income women attending two county clinics in Texas found that high CD4 count at delivery, low viral load at baseline, low levels of depression, high interpersonal support, knowledge about the benefits of adherence, and strong relationships with providers were positively associated with postpartum follow-up (19).
- An analysis of 213 medical charts from participants in a prenatal program in Texas identified factors associated with loss-to-follow up in the postpartum year; these included younger age, black race, late entry

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- A qualitative study among 18 postpartum women living with HIV in Alabama found that competing life priorities (such as work and childcare) and access to transportation were barriers to retention in HIV care (51). Facilitators to care included the desire to stay healthy for themselves and for their children, familial support, and appointment reminders.
- A retrospective chart review of pregnant women living with HIV (297 deliveries in 274 women) in Mississippi found that presentation before the third trimester was associated with optimal follow-up in the postpartum year (4).

It is evident that several barriers can prevent optimal retention in HIV care among postpartum women living with HIV. However, we found few interventions that address this issue among populations in high-income settings. This observation is supported by a 2018 evidence review which notes the limited evidence base of interventions addressing this gap (38). Nonetheless, a few interventions appear to be promising.

One study from the UK in 2011 sought to determine if a financial incentive encouraged postpartum clinic attendance among women living with HIV (52). The financial incentive was based on the high cost replacement feeding (i.e. formula); of at time, recommendation in UK that the the was to breastfeeding completely abstain from (53). Authors compared attendance and rates clinical outcomes among women who had not received the intervention (n=25), and those who had (n=26). Authors found that replacement feeding was supportive; furthermore, participants attended more appointments on average with better adherence to antiretroviral medication.

A second study done in the UK qualitatively evaluated a peer support program called Mentor Mother (54), a model of peer support (www.m2m.org). Originally developed in South Africa in 2001, the study sought to determine if this peer support program was acceptable for African mothers living with HIV in England. Mentors received 36 hours of training on peer mentorship techniques and HIV during pregnancy. Where possible, "pairing" of a mentor and mother took culture, language, and HIV experience into account. Mentoring occurred through face-to-face meetings during the prenatal phase, continuing through the postnatal period, if needed. Semi-structured and in-depth interviews among six mentors and six mentees were conducted. Key themes from the qualitative analysis included "supporting mothers to avoid mother-to-child transmission" (e.g. reinforcing medical advice and strategies to manage HIV and motherhood) and "emotional support" (e.g. role modelling and nonjudgemental acceptance). Authors concluded that the program was a successful hybrid between the Mentor Mother programs in Africa and peer support models already operating in England.

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36. European AIDS Clinical Society. Guidelines, Version 9.1 — Treatment of HIV-positive pregnant women. Available from http://www.eacsociety.org/ files/2018_guidelines-9.1-english.pdf Accessed November 8, 2018. 2018. A recent intervention in the U.S. evaluated a Perinatal Medical Case Management (PCM) program among pregnant and postpartum women living with HIV in Philadelphia (2). The PCM program is a referral-based, voluntary program designed to support pregnant women living with HIV during pregnancy and up to one year postpartum. Perinatal (i.e. before and after birth) medical case managers offer psychosocial support, address structural barriers to HIV care, and identify unmet needs. Plans for care include goal setting for disclosure, retention in HIV care, and adherence to antiretroviral therapy. Over a nine-year period, of 849 pregnant women living with HIV, 448 (53%) received PCM. Authors found that women receiving PCM were more likely to achieve viral suppression prior to delivery and were morelikely tobe retained in HIV care at one year postpartum.

An abstract (55) from the 7th International Workshop on HIV & Women (2017) outlines how a peer support intervention for postpartum women was successfully adapted out of a prenatal care model called Centering Pregnancy (56). The intervention consisted of ten two-hour sessions per pregnancy which included basic HIV facts, disclosure, medication adherence, safe sex and conception, the logistics and importance of retention in care, and infant testing after delivery. Compared to women in standard one-on-one care (n=20), women receiving the intervention (n=26) demonstrated an increase in clinic visits postpartum. Additionally, qualitative data suggested that women preferred the group model as opposed to standard care.

Finally, a recent editorial review presents interventions in lowand high-income settings that could help improve retention in care for postpartum women living with HIV in the United States (38). The authors note that the majority of studies were conducted in low- or moderate- resource settings, which may be less applicable and more difficult to adapt to high-resource settings. Nevertheless, authors suggest that some low-income interventions could be adapted to different settings. Five key action steps to improving retention in HIV care postpartum are proposed:

- 1. Increasing provider and patient awareness of poor postpartum retention, with targeted support occurring as soon as possible during pregnancy
- 2. Improving care coordination using existing resources
- 3. Implementing the Perinatal Medical Case Management program (2)
- 4. Implementing peer support interventions through adaptation
- 5. Using adapted technology-based interventions to improve engagement postpartum

37. World Health Organization, United Nations Children's Fund. Guideline: Updates on HIV and infant feeding: The duration of breastfeeding, and support from health services to improve feeding practices among mothers living with HIV. Available from http:// apps.who.int/iris/bitstream/hand le/10665/246260/9789241549707-eng. pdf?sequence=1 Accessed November 9, 2018. 2016.

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Postpartum adherence to HIV medications

Canadian guidelines recommend that "[a]ll pregnant women living with HIV should be treated with combination antiretroviral therapy regardless of baseline CD4 and viral load" (14). Of note, any risks identified due to taking antiretroviral medication while pregnant are outweighed by the benefits of treatment (57). Additionally, women living with HIV should not discontinue antiretroviral therapy postpartum, given the health benefits and associated risks (58); rather, antiretroviral therapy should be continued after delivery and reassessed by an HIV care provider (59).

Despite these recommendations, pregnancy and the postpartum period cause changes in a mother's life that may impact adherence to an antiretroviral regimen (9). One systematic review found that reaching adequate levels of adherence is especially challenging in the postpartum period (10); another found that multiple factors impact a woman's ability to adhere to her medication (44). Indeed, we identified five systematic reviews (10, 39, 43, 44, 60) that detailed antiretroviral therapy usage among pregnant or postpartum women living with HIV. However, of the individual studies included in these reviews, only a select few were conducted in high-income settings, published in the past ten years, and relevant to the research question on adherence. A few of these are described below:

- An oral abstract from the 2009 Canadian Association for HIV Research conference detailed antiretroviral therapy adherence during pregnancy and postpartum among women living with HIV in British Columbia (8). Using data from provincial databases, authors identified 84 women between the years of 1993 and 2006 that had suitable data (i.e. both prenatal and postpartum data) available for analysis. Adherence was compared across five time periods: third trimester, and three, six, nine, and 12 months postpartum. Authors found that adherence significantly decreased with each subsequent time interval of followup and was associated with lower CD4 counts at baseline and living in the Vancouver Coastal Health Authority.
- One study conducted in the U.S. from 2002–2005 assessed adherence to antiretroviral therapy among 161 pregnant women living with HIV (61). Women completed at least one self-reported adherence questionnaire late in their pregnancy and were followed until 12 weeks postpartum. Authors found that women who missed their prenatal vitamins and used illicit drugs (past or present) were more likely to have poor adherence.

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- Another study from the U.S. examined postpartum medication adherence during pregnancy and postpartum (62). Between 2001 and 2005, adherence questionnaires were administered to 399 pregnant and postpartum women living with HIV on antiretroviral therapy. At six months postpartum, women who reported complete adherence were on average two years older than those who reported non-adherence, and were more likely to be Black as compared to white or Hispanic. Authors also found that the number of women who adhered to their HIV medication decreased as other health symptoms increased.
- A third U.S. study assessed adherence rates among 519 pregnant and postpartum women living with HIV from 2002 to 2005 (7). During pregnancy, 75% reported perfect adherence; this decreased at 6, 24, and 48 weeks postpartum. Perfect adherence postpartum was associated with initiating antiretroviral therapy during pregnancy, not having AIDS, never missing prenatal vitamins, never having used marijuana, and feeling happy all or most of the time.

In a 2014, a systematic review on interventions to improve adherence to antiretroviral therapy among people living with HIV noted that a major evidence gap in adherence-enhancing interventions existed among pregnant and breastfeeding women (63). Similarly, we were only able to identify a few interventions that improved adherence among postpartum women living with HIV in high-income settings. Note that some interventions mentioned in the previous section on retention in care also address adherence (2, 52, 55). This is expected, as regular clinic visits are associated with antiretroviral adherence and viral suppression (38).

Directly Observed Therapy (DOT) is a method of drug administration where a health care professional ensures that an individual receives and takes all medication as prescribed (64). A 2010 meta-analysis reported that DOT of antiretroviral therapy had a significant impact on virologic, immunologic, and adherence outcomes (65). One study identified in this meta-analysis evaluated the issues impacting adherence to antiretroviral therapy among pregnant and postpartum women living with HIV in the U.S. territory of Puerto Rico in 2003 (66). A convenience sample of seventeen pregnant and postpartum women participated in qualitative research. Women expressed that if DOT were available, they would be willing to integrate it into their life. Notably, the dominant theme in the interviews was the potential supportive role a DOT health care professional (e.g., social outreach worker) would provide. 50. Aebi-Popp K, Kouyos R, Bertisch B, Staehelin C, Rudin C, Hoesli I, et al. Postnatal retention in HIV care: Insight from the Swiss HIV Cohort Study over a 15-year observational period. HIV Medicine. 2016;17(4):280–88.

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Postpartum women living with HIV and depression

Canadian research has demonstrated that depressive symptoms are prevalent and likely to reoccur among people living with HIV (71), and that the prevalence and severity among women living with HIV is higher compared to men (72). Furthermore, mental health concerns among pregnant and postpartum women living with HIV are widespread (11, 73). A systematic review from 2014 identified 53 studies (30 from high-income countries) examining the mental health of pregnant and postpartum women living with HIV (11). Authors concluded that globally, psychiatric symptoms, particularly depression and mental health vulnerabilities, have the potential to impact well-being, quality of life, and other important clinical outcomes in this population.

Criteria used to diagnose major depressive disorder are the same for diagnosing depression in women who are pregnant or postpartum (74). According to the latest Diagnostic and Statistical Manual of Mental Disorders (DSM-5®), published in 2013, if symptoms occur during pregnancy for four weeks after delivery, the specifier of "peripartum" is used (75). Of note, the DSM®4 (2010) used the specifier "postpartum", which referred only to onset of symptoms within four weeks of delivery (76). Despite this change between the fourth and fifth editions, it appears that several authors continue to use the term "postpartum" when specifically talking about depression after delivery.

The Canadian HIV Pregnancy Planning Guidelines include a set of recommendations regarding psychosocial and mental health related to HIV pregnancy planning and fertility (77). These recommendations include assembling an appropriate care team for the perinatal period and content suggestions for counselling sessions, though there are no specific recommendations regarding perinatal depression. The Canadian Guidelines for the Care of Pregnant Women Living with HIV and Interventions to Reduce Perinatal Transmission briefly 56. Kershaw TS, Magriples U, Westdahl C, Rising SS, Ickovics J. Pregnancy as a window of opportunity for HIV prevention: Effects of an HIV intervention delivered within prenatal care. American Journal of Public Health. 2009;99(11):2079–86.

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Several studies found in our search examined depression and other mental health concerns among pregnant or postpartum women:

- One study retrospectively examined case notes of 84 pregnancies among 76 women living with HIV in Sheffield, UK (78). Women who missed appointments and who were non-adherent to antiretroviral therapy experienced psychological problems, including self-reported depression.
- A study among pregnant and early postpartum women living with HIV in Ontario (n=77) found that HIV-related stigma increased from pregnancy to postpartum (79). Depression symptoms and perceived racism were significant predictors of overall HIV-related stigma.
- Another study evaluated the association between depression during pregnancy and HIV care outcomes (80). Of note, the study population consisted of women enrolled in the PCM program in Philadelphia, previously described (2). Women living with HIV with possible or definite depression had similar outcomes on the HIV care continuum compared to those without depression. Authors suggest that while the majority of women in the cohort experienced several psychological stressors, the intensive support provided by PCM was highly beneficial, and likely reflects the results of the study.
- A study conducted at a specialty perinatal HIV clinic with women (n=215) receiving obstetric care at Northwestern University found that maternal disclosure of HIV serostatus to family members was associated with a reduction in postpartum depression by more than half (81).
- A study in a Philadelphia hospital examining depression among women living with (n=49) and without HIV (n=113) found that childhood sexual abuse was predictive of postpartum depression among women living with HIV (82).

Interventions to address perinatal depression among women living with HIV were difficult to identify. Two systematic reviews outlining interventions for perinatal depression among women in general were identified (83, 84). However, it is important to note that there may be additional physical and psychological healthrelated risks among women living with HIV who are experiencing perinatal depression (85). Nonetheless, these two systematic reviews may aid in identifying potential strategies to explore. The first review is from 2007, and its authors found that psychosocial and psychological interventions appear to be effective in reducing symptoms of postpartum depression (84). The second is a meta-analysis from 2016, and had similar results: psychological 62. Mellins C, Chu C, Malee K, Allison S, Smith R, Harris L, et al. Adherence to antiretroviral treatment among pregnant and postpartum HIV-infected women. AIDS Care. 2008;20(8):958–68.

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The need for more research and development targeting interventions for pregnant women living with HIV is highlighted in a 2014 meta-analysis (11). This meta-analysis identified two studies that discussed programs with mental health components for pregnant women living with HIV; however, both publications are from more than a decade ago. One study (1995) outlines the Special Prenatal Care Program at Bellevue Hospital in New York city, which takes a multifaceted care approach and recommends integration of services in order to fully support a mother living with HIV (86). A second study (2004) details the Whole Life project, a model of care that integrates comprehensive mental health services, primary HIV care, and obstetrical/gynecological care at one site (87). A collaboration of the Psychiatry and Obstetric/Gynecology Departments at the University of Miami School of Medicine, the article outlines the conceptualframeworkandlessonslearned during integration efforts.

A third study identified in the aforementioned review is more recent (2010), and describes how an evidence-based cognitive behavioural therapy intervention to prevent perinatal depression was adapted for two different Latina immigrant communities in the U.S. (88). Authors note the public health dilemma of whether or not to administer evidence-based interventions in settings that are culturally and socioeconomically diverse, and suggest that using empirical data (i.e. practical experience) to drive decisions in adapting evidence-based interventions may be a practical step forward. Other authors support using this strategy to adapt interventions (89, 90).

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Factors That May Impact Local Applicability

This review attempts to synthesize research evidence on postpartum women living with HIV in high-income settings and is not meant to replace medical advice. The focus was on high-income countries due to the socioeconomic and cultural differences between high-, middle-, and low-income settings. However, it should be noted that differences among populations in high-income settings also exist and have not been accounted for. Finally, not all cited programs, interventions, or curricula have been rigorously evaluated. Therefore, caution should be used when considering implementation.

🛢 What We Did

We searched Medline using a combination of text term HIV and (text terms [postpartum or childbirth or child birth or after delivery or post partum or postpartum or postnatal or after pregnancy] or MeSH terms [Postpartum Period or Lactation]). All searches were conducted on September 26, 2018 and results limited to English articles published from 2010 to present. Reference lists of identified literature reviews and systematic reviews were also searched. The search yielded 1,445 references from which 90 studies were included. Sample sizes of primary studies ranged from 12 to 980. Therefore, caution should be used when considering implementation.

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Rapid Response: Evidence into Action

The OHTN Rapid Response Service offers quick access to research evidence to help inform decision making, service delivery and advocacy. In response to a question from the field, the Rapid Response Team reviews the scientific and grey literature, consults with experts, and prepares a brief fact sheet summarizing the current evidence and its implications for policy and practice.

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