Economic and Social Factors are Some of the Most Common Barriers Preventing Women from Accessing Maternal and Newborn Child Health (MNCH) and Prevention of Mother-to-Child Transmission (PMTCT) Services: A Literature Review

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Abstract Support to health programming has increasingly placed an emphasis on health systems strengthening. Integration of prevention of mother-to-child transmission (PMTCT) and maternal and newborn child health (MNCH) services has been one of the areas where there has been a shift from a siloed to a more integrated approach. The scale-up of anti-retroviral therapy has made services increasingly available while also bringing them closer to those in need. However, addressing supply side issues around the availability and quality of care at the health centre level alone cannot guarantee better results without a more explicit focus on access issues. Access to PMTCT care and treatment services is affected by a number of barriers which influence decisions of women to seek care. This paper reviews published qualitative and quantitative studies that look at demand side barriers to PMTCT services and proposes a categorisation of these barriers. It notes that access to PMTCT services as well as eventual uptake and retention in PMTCT care starts with access to MNCH in general. While poverty often prevents women, regardless of HIV status, from accessing MNCH services, women living with HIV who are in need of PMTCT services face an additional set of PMTCT barriers. This review proposes four categories of barriers to accessing PMTCT: social norms and knowledge, socioeconomic status, physiological status and psychological conditions. Social norms and knowledge and socioeconomic status stand out. Transport is the most frequently mentioned socioeconomic barrier. With regard to social norms and

knowledge, non-disclosure, stigma and partner relations are the most commonly cited barriers. Some studies also cite physiological barriers. Barriers related to social norms and knowledge, socioeconomic status and physiology can all be affected by the mental and psychological state of the individual to create a psychological barrier to access. Increased coverage and uptake of PMTCT services can be achieved if policy makers and programme managers better understand the barriers that may prevent their potential target population from taking up and adhering to their services. The categorisation presented in this review provides further insight into the type of barriers that may exist.

Keywords PMTCT · MNCH · Adherence · Access · Retention in care

Introduction

When WHO prevention of mother-to-child transmission (PMTCT) guidelines are followed, it is possible to reduce HIV transmission from the mother to the child from 15–40 % to 5 % or less in the breastfeeding population, the case in most resource-limited settings, to less than 2 % in a non-breastfeeding population [1]. PMTCT interventions should be rolled out within the context of antenatal care (ANC), which is a component of maternal and newborn child health (MNCH). Pregnancy is often the first time that women of reproductive age have contact with the formal health sector. It represents, therefore, an opportunity to test and provide counselling for HIV and to subsequently enrol women living with HIV in PMTCT programmes.

The global coverage of PMTCT programmes has increased steadily since the first WHO PMTCT guidelines were published in 2000. Significant changes have occurred

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in PMTCT, with improvements in guidance on infant and young child feeding practices and the use of antiretroviral medication. Despite an increase in coverage, in 2011, 57 % of pregnant women living with HIV in low and middle income countries received effective drug regimens to prevent HIV transmission to their child before, during or after delivery [2]. While there may have been an assumption that PMTCT services would integrate relatively seamlessly into broader MNCH services, this has unfortunately not been the case.

Despite improvements in the roll-out and uptake of PMTCT programmes globally, an estimated 3.3 million children were living with HIV in 2011 [3]. Poor adherence to PMTCT medication [4–6], in addition to low levels of access, uptake and retention in PMTCT care for pregnant and lactating women, contribute to persistently high levels of mother to child transmission with low levels of adherence to PMTCT regimens being well documented in the literature. Many women drop out of PMTCT care, with only 15–30 % of women being retained [7]. Adherence is one part of overall access to care which encompasses testing, initiation, uptake, adherence to medication and retention in care (see Table 1 for definitions).

The global figures presented above point to an urgent need to address the barriers which are preventing women from accessing PMTCT care, from adherence to

medication and to retention in care in the longer term. In settings where PMTCT services are in place, a significant proportion of women fail to access care services [8, 9]. Given that the PMTCT service gap was so large for many years, policy makers and funders have first focused on increasing the availability of services and improving quality will be next. In this paper we explore whether the scale up of PMTCT services, in terms of provision of supply side inputs, has been adequately complemented by actions on the demand side, which enable women to use the services. Stringer et al. [10] have outlined the critical pathways in the so-called ‘PMTCT cascade’ that women must negotiate in order to achieve PMTCT prophylaxis (see Fig. 1). They linked process data from milestones in PMTCT care and treatment with the final outcome of infants born without HIV, and noted that younger women and women who have fewer antenatal visits are more likely to receive inadequate prophylaxis. While they did not assess why women fall off the cascade, they mentioned stigma and fear of disclosure as important barriers.

In this paper we examine the literature to determine common reasons for women to fall off this cascade (see Fig. 1) and disengage from PMTCT care and treatment. We have already noted that there has been considerable investment in supply elements particularly at health centre level which, as illustrated by global utilization figures, has not lead to sufficient access. Therefore, we particularly want to identify which factors hamper demand, and classify those into thematic areas that are useful from a program design perspective. Table 2 presents examples of some of the demand side barriers that are found in the literature. We will first discuss how accessing MNCH services is critical to be able to receive PMTCT services and then present the methodology and results of our literature review for categorizing demand-side barriers to accessing PMTCT services.

MNCH has been defined as a collection of eight service packages. PMTCT care cuts across various MNCH service packages and is particularly intertwined with ANC [11]. A number of studies have noted that adherence to PMTCT medication is associated with ANC attendance, with non-adherent women shown to make fewer ANC visits [4, 12]. ANC is one of the key MNCH services and has the potential to save lives. It is, therefore, important to understand what factors influence the uptake of and retention in ANC. Firstly, there are women who never actually enter MNCH care. Secondly, there are those who enter care, but do not reach the recommended treatment milestones such as the minimum number of four ANC clinic visits recommended by WHO. ANC has been more successful than some of the other MNCH services in terms of attaining an adequate level of coverage globally. Worldwide 71 % of women receive ‘any’ ANC with the

Table 1 PMTCT care and treatment terminology

1. PMTCT care and treatment components—These are the elements that make up access to PMTCT. This includes testing, uptake of services, initiation, adherence to medication and retention in care.
2. Access—A complex concept with at least four aspects requiring evaluation. Access is measured by 1. Service availability 2. Utilisation of services and barriers to access 3. Relevance and effectiveness and 4. Equity [40].
3. Uptake—Uptake refers to the first time services (e.g. ante-natal care, PMTCT or ARV treatment) accessed. While the term signals an assumption of a longer term commitment, uptake does not say anything about adherence.
4. Adherence—Adherence (ART, TB): refers to how closely the ART or TB client follows the prescribed treatment regimen. Good adherence involves taking the correct medication at the right time every day, taking the correct dosage every time, and following other instructions on how to take the medication.
5. Attendance—Attendance refers to physically presenting at the clinic or at the health centre to access services. It often coincides with adherence, but is broader in that it does not always refer to the taking of medication. One can also attend without complying with the prescribed behaviour. Attendance is frequently used when describing a pregnant woman’s compliance with a specific number of pre-natal visits.
6. Compliance—Compliance describes adopting the behaviour prescribed by the health protocol or medical personnel.
7. Retention in care—Retention in service or retention in care describes repeated attendance at the health centre.

Fig. 1 PMTCT treatment cascade adapted from Stringer et al. [10]

corresponding figure for sub-Saharan Africa being 69 %. In sub-Saharan Africa, the proportion of women attending four ANC visits is 54 % [13].

It has been estimated that about 500 000 women die from complications of childbirth and pregnancy every year [14]. Women and their babies are most at risk of death during childbirth and the first days of the postnatal period with over half of all maternal and neonatal deaths occurring at this time [13]. Despite the importance of this period, the childbirth clinical-care and postnatal care packages are not accessed by enough women. In 2011, UNICEF reported that only 45 % of women in sub-Saharan Africa had a skilled attendant at birth [15].

An analysis of 23 Demographic and Health Surveys (DHS) in sub-Saharan Africa looking at postnatal coverage found that only 13 % of women presented for a postnatal visit. The analysis also showed for example that in Ethiopia

90 % of mothers had not received any postnatal care in the 6 weeks after birth [13].

For PMTCT services to be implemented, MNCH services such as ANC, early pre- and post-partum care, delivery at a health facility and postnatal care services, are some of the services which need to be in place. At the time when single dose nevirapine, rather than regular anti-retroviral therapy (ART), was used for prevention of mother to child HIV transmission, it was necessary for women to take the nevirapine at home in the event of a home birth. In contexts like Uganda, where roughly 70 % of women deliver at home, women needed to take single dose of their own volition as well as administer ART to the newborn or return to the clinic for it to be administered [16]. It is difficult to ensure that women take single-dose nevirapine at the right time, especially if they are not supervised or have not been provided with medication to take home with

Table 2 Examples of demand side barriers found in literature search

	Definition	Barrier	Definition	Examples from literature
Demand	The utilization of PMTCT services	Socioeconomic status ^a	Resource situation (including financial) of the beneficiary	Transportation costs, financial difficulties, wealth quintile, competing demands for resources, education level, age, place of birth, marital status
		Social norms and knowledge ^a	Interactions of the beneficiary with other members of the household and members of society at large. Knowledge of HIV and HIV treatment	Close relationships, difficulty of disclosing to partner, social support, pressure to share medications, stigmatization, gender relations, inequality, decision making at household level, discrimination, exclusion, knowledge of HIV and HIV treatment, stigma towards use of infant formula/infant feeding, use of a traditional birth attendant
		Physiology ^a	Effects of illness and treatment on body function	Side effects, being asymptomatic, sickness
		Psychology	Psychological situation of the individual (including subjective beliefs of other barriers)	Fear of disclosing HIV status, mental health, health beliefs, level of trust in providers, interrupted personal routine, implications of having a chronic disease

^a Barriers related to socioeconomic status, social norms and knowledge, and physiology may exist objectively or also only subjectively (i.e. fear of unbearable side effects, even though they may actually be tolerable)

them in the event of a home birth. Giving take home medication may also be perceived as counterproductive in contexts where health policy is to encourage women to give birth at health clinics. Notably home birth is significantly associated with low levels of compliance with single-dose nevirapine as reported by a number of studies [4, 12, 17].

Many barriers to MNCH are typically related to purchasing power. A look at the MNCH literature notes that access to treatment is linked to socioeconomic status and therefore varies with the different wealth quintiles. In Africa, 80 % of women from the richest quintile attend three or more ANC visits against only 48 % from the poorest quintile [13]. Similarly, analysis of DHS data from 45 resource-limited settings showed that 84 % of women in the highest quintile had births assisted by a skilled birth attendant compared to only 32 % in the lowest quintile [13].

Poor and vulnerable groups experience a greater burden of disease while at the same time having less access to health services [18]. A review looking at inequalities in health care use and expenditures found that wealthier households have a higher likelihood of obtaining care when they need it [19]. Using expenditure as a proxy for income, the review found that (1) those in higher wealth quintiles are more likely to be seen by a doctor; (2) in all but one of

the eight countries reviewed richer groups are seen to have greater access to medicines when they become ill; and (3) richer people spend more on health care in absolute terms than do poorer people [19].

While access to MNCH services is far from satisfactory in many low income contexts, PMTCT care also has a set of barriers which have to be overcome after accessing MNCH. In addition to low ANC attendance and home births being also associated with low access to PMTCT, there are also predictors of low adherence in PMTCT cited in the literature. Interestingly, while they include economic considerations, they go beyond. Being younger, less educated and not having disclosed one's status to a partner or family members are all associated with lower levels of adherence to PMTCT [4, 5, 10, 12, 17, 20].

The use of standard ART regimens for all pregnant women living with HIV for life, known as option B+, as opposed to other regimens like single dose nevirapine, is a recent recommendation [21]. Therefore, most of the research on adherence to ART in pregnant women relates to the use of single dose nevirapine or zidovudine. Treatment for life may be more difficult to adhere to.

The PMTCT cascade has been defined as a critical pathway of events which must occur for PMTCT prophylaxis to be delivered [22]. Figure 1 shows the main milestones that need to be achieved in order to reach the desired

end result of nevirapine exposure based on nevirapine detected in cord blood and the observation of infant ingestion of nevirapine. It represents an example of the PMTCT cascade, albeit based on the no longer recommended single dose nevirapine regimen. The woman has to be offered a test for HIV, accept testing and then must return to receive her results. Nevirapine needs to be dispensed to the pregnant woman, the medication should then be taken at the time of labour and in addition the newborn should receive nevirapine prophylaxis. The figure illustrates the fall off that occurs along the way and shows that in this particular study from an initial 3,196 seropositive deliveries, in a context where services are in place, the actual coverage as defined above was 1,725 maternal-infant pairs ingesting nevirapine, a success rate of 54 %. This figure is based on the study population and excludes women who did not receive ANC services or who received them in locations where no, or only some, PMTCT services were available.

Other authors have reported similar findings for the adherence to ingesting nevirapine at birth. Kuonza et al. [4] showed a mother-infant pair non-adherence rate of 42.9 %. Mirkuzie et al. [23] showed 68 % of mother-infant pairs ingesting nevirapine at birth. A study by Barigye et al. [5] showed 38 % of mother-infant pairs achieving full adherence. A cohort of women followed by Kirsten et al. [20] noted that only 8.3 % of women were able to achieve levels of adherence of 80 % or more in all phases. In another study by Stringer et al. [9] 32 % of women living with HIV, who were given nevirapine in antenatal care, did not in fact ingest the tablet.

Methodology

The main search strategy consisted of searching the PubMed electronic database using combinations of key words including PMTCT/ART and adherence/compliance/uptake/access/initiation/retention in care and barriers/obstacles/factors. Secondly, relevant papers suggested by authors in this area were considered. Thirdly, a thorough review of the papers found in steps one and two generated further references.

The search generated 19 studies which discuss barriers to PMTCT care, 6 were mostly quantitative, 13 mostly qualitative with a couple of studies having both qualitative and quantitative elements. The concept of access encompasses a number of subcomponents and definitions vary among authors. Some studies define adherence as the extent to which patients' take their prescribed medication [8, 20, 24]. Others define adherence as returning to clinic for an appointment [6], and some did not give definitions for the terms used. Given this lack of agreement on

definitions used, the authors had to take a pragmatic approach to both the categorisation of barriers as well as to deciding which component of treatment was the principal focus of each of the studies.

The main inclusion criterion for this review was primary qualitative or quantitative research with an explicit objective to identify, quantify or explain barriers to accessing PMTCT care and treatment. Only papers from resource-limited settings were included. While most of the studies found look at both supply and demand side barriers, the focus of our review was on demand side barriers. The search yielded relatively fewer quantitative than qualitative studies. We used information from quantitative studies to get a better idea of where people drop from the cascade and who these people are, and the information from qualitative studies allowed us to gain a better understanding of why people do not access care or drop out.

In relation to variation in research participants, some studies focused on women enrolled in PMTCT programmes with some taking ART and others not. In addition, in many countries ART and PMTCT treatment guidelines changed over the course of the period reviewed.

The objective of this review was to categorise the barriers that prevent women's access to PMTCT as described in the literature. Although some of the papers group certain barriers thematically none of them propose a categorisation that can represent all the barriers reported in the literature [24]. In instances where barriers are identified but not classified or where barrier classification is not in line with the barrier categorisation presented in this paper, we have reassigned the barrier according to the logic of our own categorisation framework. For example, O'Gorman et al. [25] group the barriers of lack of male involvement and using a Traditional Birth Assistant (TBA) under the heading of community factors. In our table we categorise both of these barriers as social norm and knowledge barriers.

In order to develop the categorisation of barriers, the team (MOh, NG) performed an analysis of all the barriers reported in the literature to identify appropriate descriptive themes for the barrier categories.

We first re-labelled some barriers using specific broader terms e.g. lack of partner support (some called this lack of male involvement). Once we agreed on the larger categories, i.e. socioeconomic, social norms and knowledge, physiology and psychology, we assigned each barrier to a category. The first three categories are in themselves barriers that impede access to care and treatment. The barrier category of psychology is a complex one. Firstly it can act as a barrier through the way HIV related disease impacts on the mental health of the individual. Secondly, the subjective perception held by the individual of the other barriers may compound those so that one could consider a

separate psychological barrier. For example, a person living with HIV may fear or worry based on hearsay that the increased need for food while taking medication will be insurmountable, when in fact this may not be the case.

Findings

Socioeconomic Status Barriers

Socioeconomic barriers result from the economic or socio-demographic characteristics of the person living with HIV or the affected household. 13 of the 19 studies cited any type of socioeconomic barrier. By seeking care, those in need of PMTCT will suffer a loss of earnings, meaning that accessing care becomes an opportunity cost.

Of the socioeconomic barriers identified, transport barriers were the most consistently cited. While some of the quantitative studies do not capture distance to the clinic and, therefore, perhaps unintentionally omit this barrier, 8 of the qualitative studies identified transport costs as a barrier to accessing services [6, 25–31]. Only one of the quantitative studies explored transport as a barrier and there was no significant association between transport and adherence to PMTCT [20].

A quantitative study by Mbonye et al. [32] covering 10,706 women in rural Uganda investigated decision-making and access with regards to family planning, HIV testing and delivery at health facilities. It found that socioeconomic variables had limited influence on testing, given that testing is part of standard health care services and the likelihood to get an HIV test does not vary by wealth quintile or education, but by age, with adolescent girls less likely to get tested. However, for access to family planning, lower wealth quintile and less education were predictors of poorer access. For delivery at health facilities, younger age and lower education made such delivery less likely. On all three themes the study cross-tabulated the finding against who makes decisions in the household, showing that women usually have poorer access to health services when they are not involved in the decision-making process. As the study did not control for distance to health facilities, it was not possible to determine to what extent this could explain the greater access among the higher wealth quintiles, or may have confounded some of the other relationships found.

A qualitative study with 45 participants using thematic analysis by Duff et al. [26], also in Uganda, categorized barriers into five broad areas: economic constraints, HIV-related stigma, non-disclosure of HIV status, health care factors, and HIV/AIDS and ART knowledge. Of the economic constraints barriers, costly transport in order to attend monthly check ups was the greatest barrier to treatment.

It is obvious that poverty limits the ability to access healthcare especially when transport costs are considerable. This is a good example of a barrier where demand and supply meet. The cost of reaching the clinic is an issue for poor households. It can be addressed by providing cash or vouchers (on the demand side) or by bringing services closer to those in need (on the supply side). It is important to note that it may not always be possible to bring specialized services to community or district level and there will always be a need of referral ‘up the system’.

Social Norm and Knowledge Barriers

Family members and society at large can influence individual behaviour through social norms. At times, these social norms can result in barriers to accessing care. In some settings, the male head of household or a female figure at household level, such as the mother in law, may be the main decision maker when it comes to accessing healthcare for family members, including women in need of PMTCT [25]. A range of social norms and knowledge barriers were identified in the papers with most of them originating from the negative repercussions that disclosing ones status may have on close relationships, especially with partners. Eleven of the qualitative studies cited any type of social norm and knowledge barrier with 4 of the quantitative studies reporting barriers in this category. Some of the social norm and knowledge barriers included stigma, discrimination, lack of male partner support, effects of disclosure, the influence of men and other women living in the household on the woman’s health decision-making, lack of community support, domestic violence and lack of or incorrect knowledge about HIV. However, context in studies differed—while in some studies most women were married or living in a relationship, two-fifths of the women in one study from Botswana said they were single or not in a long term relationship [33]. While this may imply less access to resources, it also meant they had more control over their decision-making and fear of partner disclosure or stigma was less of an issue. Among single women, 85 % said the child’s father had no influence on their decision making to participate in the PMTCT programme.

Nine of the qualitative the studies reported that the lack of male partner support was a significant barrier to seeking care [6, 8, 24, 25, 27–30, 34]. Two of the studies one of them quantitative, showed that when women and men make decisions together, adherence is usually better [6, 32]. A quantitative study by Kirsten [20] found that the only factor significantly influencing adherence to PMTCT in the antenatal phase was disclosure to the partner, family or friends. Therefore, interpersonal relations, especially those with the partner, can influence the decision to access treatment. Patient concerns around stigma, discrimination

and hostile reactions of family and community are realities in many communities and thus play a significant role in the decision to come forward and test, enrol and be retained in PMTCT care.

A mixed quantitative and qualitative study by Mepharm et al. [24] in South Africa explored the social barriers to accessing PMTCT in more detail. This study used unstructured interviews amongst pregnant women, randomized to either receive short course therapy or full ART. The authors present three broad headings in order to interpret the social barriers. The categories are listed as intrapersonal reasons, interpersonal reasons and social reasons. The study gives specific examples where negative perceptions and the resulting hostile actions of partners and family impede adherence to treatment. Some participants cited the risk of domestic violence should they attend clinic, others have to hide their antiretrovirals because a family member may destroy or steal them.

From reviewing the literature the issue of non-disclosure to partners and others in the environment is a complex one which has many dimensions. The findings on partner relations point to a vicious cycle where there is a legitimate fear of disclosing one's status and therefore a need to hide the need for care. In many cases this fear is very real and disclosure may put the woman and the baby's life at risk.

Five of the qualitative studies noted that lack of information and poor or incorrect knowledge regarding HIV in general and specific aspects of HIV care such as infant feeding within PMTCT acted as barriers to accessing treatment [8, 24, 26, 35, 36]. Knowledge of the referral process as well as HIV and treatment options stand out in three studies in particular [6, 8, 29]. Muchedzi et al. [29] showed that having good HIV knowledge makes adherence three times more likely. Murray et al. [8] explored the issues of information on HIV as well as other psychological issues such as lifestyle changes and mental illness in greater detail. One of the most commonly mentioned barriers in the study was the lack of information about ART and HIV. The authors concluded that there is a need to provide information that is relevant to local concerns especially in relation to women fulfilling their societal roles as mothers and carers. The studies above illustrate that knowledge is somewhere at the intersection of supply and demand as it is an outcome of supply of information through counselling, education, and social marketing and for demand in the way that the individual seeks out this information and how they put it to use, or not. It is important to note that stigma could also drive (or prevent) dissemination of knowledge (and can cause the dissemination of incorrect information and rumours). In any case, correct knowledge clearly empowers informed decision making and, therefore, helps reduce barriers.

Physiological Barriers

In the context of HIV, abnormal physiological processes can occur as a result of the illness itself or due to undesirable effects of the treatment.

ART in the setting of PMTCT has the additional challenge that living with HIV but being asymptomatic can mean that there is less impetus to seek care because of the absence of overt symptoms. In the case of general HIV treatment, most individuals who start ART in resource-limited settings do so when they have become symptomatic [37]. ART in such individuals often greatly transforms quality of life. Frequently, the so-called 'Lazarus effect' is experienced, i.e. symptoms disappear quickly or lessen and, as a consequence, patients are more forgiving of the disease complications and side-effects that can occur during the early phase of ART. In contrast, many women who are eligible for ART within the PMTCT setting start treatment at earlier stages when they do not have overt symptoms and will not experience such gains and, as a consequence, are less tolerant of side effects and complications [30]. This possibility is now even stronger with pregnant women being recommended to use the same ART regimen as other people living with HIV.

Physiological barriers are the least reported in the literature. Three of the qualitative studies cited physiological barriers while the issue was not reported in the quantitative papers [6, 26, 30]. The main forms of barrier cited were lack of symptoms reducing the need to seek care, and sickness preventing access to care and treatment services.

An explorative qualitative study with 116 participants in Kenya found that women enrolled in the PMTCT programme did not see the benefits of follow up and prophylaxis as compelling reasons to start treatment [30]. Another study on barriers to ART in the ANC context found that 60 % of people interviewed were deferring treatment initiation until their health deteriorated significantly [26].

Psychological Barriers

Psychological barriers emerge as a result of mental health, but also from perceptions and beliefs associated with some of the other barriers presented above. Beliefs held by people in a person's environment (social norms and knowledge) as well as socioeconomic and physiological barriers can influence the psychology of the individual. Therefore, psychological barriers can arise from the subjective perception of the other barriers. The example of social norm and knowledge barriers showed that in many contexts when women access treatment, negative consequences can result. However, the fear of such consequences

can in fact be out of proportion with the risk itself and this fear can then become an access barrier.

Ten of the qualitative and three of the quantitative studies cited various psychological barriers, including interrupted personal routines, coping with the implications of having a chronic disease, fear of abandonment, fear of expenses, fear of HIV testing and stigma, mental illness with feelings of helplessness including depression and health beliefs.

The study by Murray et al. [38] is the only study which flags the issue of mental illness such as depression and the potential impact it has on adherence. The study noted that many of the individuals interviewed displayed feelings of hopelessness and depressive etiology. The authors cite other studies in non-PMTCT ART settings which found links between poor adherence and mental illness. More research has been done in developed country contexts on how HIV adherence is strongly associated with mental health.

Discussion

Table 3 describes in detail the main findings of each of the studies presented in the findings section above. The table presents the main barrier categories found in each of the studies while also presenting the components of care that

each of the papers focus on. Table 4 brings all this information together in more detail. Most of the barriers identified were either socioeconomic or social norms and knowledge barriers. The main component of care described by most of the studies was adherence to treatment. Most of the studies did not prioritize the barriers by severity. A handful of the qualitative studies list barriers by severity while the rest of the qualitative studies list the most common ones without reference to frequency or severity [8, 29, 30]. In general terms both supply and demand barriers are interlinked, with transport barriers being a good example of this. We found that many of the demand barriers, as well as their categories, were interlinked.

In this review we propose that improving PMTCT outcomes requires paying adequate attention to both the supply of health care services as well as to the ability of women to access the services—the demand for care. Compared to the barriers to accessing MNCH, which are largely related to economic status, women face several additional barriers to accessing PMTCT services and staying in care.

The types of barriers and consequently the barrier categories rarely act alone. The vast majority of the studies reviewed reported on more than one barrier category and also found that they interacted. For example, psychological barriers can arise from the subjective perception of the other barrier, which may either magnify or reduce the

Table 3 Summary of literature findings

Barrier category	Number of quantitative and qualitative studies with barrier type	Countries where studies were carried out (n)	Study populations (n)	Components of care (n)
1. Social norms and knowledge	15	Uganda (2), Zambia (2), Kenya (1), Botswana (2), South Africa (2), Rwanda (1), Malawi (3), Vietnam (2), Indonesia (1)	Women in PMTCT care (9), randomly selected household participants (1), women living with HIV within ANC (1), women living with HIV (1), community members (1), supporters and health care workers (1), Post natal PMTCT (1)	Access (4), adherence (10), retention-in-care (1)
2. Socioeconomic status	13	Uganda (3), Malawi (3), Zambia (1), Tanzania (1), Rwanda (2), Zimbabwe (1), Kenya (1), Vietnam (1), Indonesia (1), South Africa (1)	Women in PMTCT care (6), women living with HIV within ANC (2), randomly selected participants (1), women living with HIV (1), community members (1) supporters, health care workers (1) post natal PMTCT (1)	Access (7), adherence (5), retention-in-care (1)
3. Psychology	13	Botswana (2), South Africa (3), Uganda (3), Zambia (1), Kenya (1), Malawi (2), Vietnam (1)	Women in PMTCT care (9) randomly selected participants (1), women living with HIV (2), post natal PMTCT (1)	Access (9), adherence (3), retention-in-care (1)
4. Physiology	5	Zambia (2) Kenya (1) Malawi (1) Uganda (1)	Women in PMTCT care (3) women living with HIV within ANC (1) post natal PMTCT (1)	Access (3), adherence (2)

Table 4 Detailed description of studies found in the literature search

Study	Setting	Barriers identified	Design	Component of care	Size	Inclusion criteria	Key findings
Quantitative studies							
1 Eide et al. [33]	Botswana	Social norms and knowledge, psychological	Multiple choice questionnaire	Access	52	PMTCT programme participants	Along with citing supply side barriers, this study identified social norm and knowledge barriers as well as psychological barriers. Specifically the demand side barriers cited related to; disclosure of HIV status, taking an HIV test, the stigma related to artificial feeding, being seen to use artificial feeding as well as the maintenance of confidentiality. Interestingly the study noted that programme users saw home visits by health workers as stigmatizing although this mode of care was used to bring the service closer to the service users.
2 Peltzer et al. [41]	South Africa	Social norms and knowledge, psychological	Questionnaire	Adherence	139	Women living with HIV	This study looked at the factors associated with adherence to short course PMTCT prophylaxis. The main barriers identified were social norms and knowledge. Discrimination, disclosure and lack of male involvement are the most significant barriers found in the study.
3 Mbonye et al. [32]	Uganda	Socioeconomic, psychological	Questionnaire	Access	10,706	Randomly selected participants	This was a household survey carried out to understand HIV care seeking practices and barriers to PMTCT. The main findings were that economic status influences access to PMTCT. The study showed that socioeconomic factors had limited influence on testing as testing is part of standard health practice. The likelihood of getting an HIV test did not vary by wealth quintile or education, but by age—with adolescent girls less likely to get tested.
4 Albrecht et al. [17]	Zambia	Socioeconomic, social norms and knowledge, physiological	Data collection from clinical information	Adherence	760	Women living with HIV within ANC	This study found significant differences in adherence in relation to place of birth. Non-adherence was four times higher with home births. Poor health status of the infant at delivery was also strongly associated with non-adherence. Other important findings were that, disclosure of HIV status, male participation in HIV testing, and socioeconomic status were not predictive of adherence in this population.
5 Kirsten et al. [20]	Tanzania	Socioeconomic	Questionnaire, clinical information	Adherence	122	Women living with HIV within ANC	This was an observational study of women living with HIV seeking ANC, carried out in a government hospital in Tanzania. The risk factors associated with inadequate adherence to PMTCT prophylaxis were; (1) Maternal age < 24 years (2) Not participating in an income generating activity (3) Enrolment before 24.5 weeks. It was also shown that women who disclosed their HIV status were significantly more adherent in the pre-delivery period.

Table 4 continued

Study	Setting	Barriers identified	Design	Component of care	Size	Inclusion criteria	Key findings
6 Delvaux et al. [12]	Rwanda	Socioeconomic, social norms and knowledge	Closed-ended questionnaire	Adherence	236	Women in PMTCT care	This study explored the determinants of non-adherence in a number of government health centres offering PMTCT. The study identified both supply and demand side barriers. On the supply side the study found that one-third of non-adherent women had not received the required medication from the health care worker. On the demand side the study showed that unmarried women, lesser educated women and women who had made two or less ANC visits were more likely to be non-adherent. Not having disclosed their HIV status to somebody other than their partner was also linked to non-adherence in mother-infant pairs.
Qualitative or both quantitative and qualitative							
1 Duff et al. [26]	Uganda	Socioeconomic, social norms and knowledge, psychological	Interview, focus discussion groups	Access	45	Women living with HIV	This study identified the most significant barriers to accessing PMTCT services. The most commonly cited were transport issues, non-disclosure, stigma and negative attitudes of health care workers. An important finding was that financial constraints determined access even if the patients were knowledgeable and well intentioned about taking the medications.
2 O'Gorman et al. [25]	Malawi	Socioeconomic, social norms and knowledge	Interviews, focus discussion groups	Adherence	70	Community members	This study looked at the factors which influence women taking nevirapine for PMTCT. The study separated barriers into hospital attendance factors and community factors. The main findings were that transport, the attitude of health workers, and that perceptions within the community were significant barriers. In relation to community the paper explored of the bio-psychosocial model of health care where the mother is not the only decision maker especially in a matrilineal culture such as Malawi.
3 Murray et al. [8]	Zambia	Social norms and knowledge, physiological, psychological	Free listing, key informant interviews, and qualitative data collection methods	Adherence	80	Women in PMTCT care	This study mainly identified social norm barriers such as the effect on interpersonal relationships especially with partners, disclosure, stigma and affective states on access to services.
4 Muchedzi et al. [29]	Zimbabwe	Socioeconomic	Interview, focus discussion groups	Access	147	Women in PMTCT care	This study mainly cited health service barriers to access. The study was carried out in an urban setting and the main conclusions were that there is a need for developing better referral tools as well as better coverage of CD4 testing. Stigma was not seen as a barrier in this study.

Table 4 continued

Study	Setting	Barriers identified	Design	Component of care	Size	Inclusion criteria	Key findings
5 Otieno et al. [30]	Kenya	Socioeconomic, social norms and knowledge, physiological, psychological	Cross sectional study	Access	116	Women in PMTCT care	This paper discussed the barriers that affect the transition from PMTCT to ART treatment in women referred for care. The most common barriers cited were transport, stigma, partner factors and health care worker attitudes. Factors thought to facilitate access were health education, counselling, free services and compassion.
6 Kasenga et al. [28]	Malawi	Socioeconomic, social norms and knowledge, physiological, psychological	Interview	Access	24	Women in PMTCT care	This study explored women's experiences of a PMTCT programme in rural Malawi. The study mainly identified social barriers related to non-disclosure, to family and partners, the difficulty related to swallowing NVP without others seeing. Distances to health facilities were also seen as a barrier.
7 Nguyen et al. [36]	Vietnam	Social norms and knowledge, psychological	interview	Access	52	Women in PMTCT care	This study dealt with barriers to PMTCT access in a middle income resource limited setting. Although the barriers identified in this context were similar to African contexts, the fear of disclosure, discrimination and lack of confidentiality as well as negative interactions with health care workers were highlighted. Despite being comparatively well resourced, the Vietnamese setting had supply issues related to quality of counselling and availability of ART at the health centres.
8 Hardon et al. [42]	Vietnam Indonesia	Socioeconomic, social norms and knowledge	Observation, focus discussion groups, interviews	Access	200+	Women in PMTCT care, Supporters, health care workers	This study compared the dynamic of care between women and health care workers in Vietnam and Indonesia within PMTCT. In both contexts it was found, that there are high levels of HIV testing with a harm reduction perspective employed without enough emphasis on care and treatment. Although both contexts studied had their challenges it was noted, that the rights to confidentiality were not as respected in Vietnam as they were in Indonesia. This study placed an emphasis on the importance of quality interactions between staff and the patient.
9 Bwirire et al. [27]	Malawi	Socioeconomic, social norms and knowledge, psychological	Focus discussion groups	Retention-in-care	25	Women in PMTCT care	This study was conducted with pre and post natal mothers to explore the reasons for loss to follow up in the PMTCT setting. Six barriers were identified: 1. Not being prepared for HIV testing 2. Fear of stigma, discrimination 3. Lack of support from husbands 4. Fear of having to use artificial feeding 5. Long waiting times and 6. Transport costs.

Table 4 continued

Study	Setting	Barriers identified	Design	Component of care	Size	Inclusion criteria	Key findings
10 Kebaabetswe et al. [34]	Botswana	Social norms and knowledge, psychological	Interviews	Access	40	Various	This study explored the barriers to participation in a PMTCT programme with the following barriers being noted: (1) HIV testing/known status (2) Stigma towards infant feeding formula (3) Lack of male partner support (4) Negative attitudes of health care workers.
11 Nassali et al. [6]	Uganda	Socioeconomic, social norms and knowledge, psychological, physiological	Questionnaire, focus discussion groups	Access, adherence	296	Post natal PMTCT	This study determined the rate of adherence to postnatal PMTCT care and also explored the factors which motivate adherence and hinder adherence. The main hindrances to adherence based on feedback from women who did not return were: fear of disclosure and fear of divorce or separation upon disclosure, transport costs, and lack of clinical symptoms.
12 Mepharm et al. [24]	South Africa	Socioeconomic, social norms and knowledge, psychological	Interviews	Adherence	100	Women in PMTCT care	This study explored the challenges to adherence within the PMTCT context. Many of the barriers identified were social in nature including; non-disclosure, domestic violence and conflicting messages from traditional healers. The impact of stigma and health beliefs, in general were underlined in this study.
13 Laher et al. [35]	South Africa	Psychological	Focus discussion groups, Interviews	Access	45	Women in PMTCT care	This study explored the reasons for incident cases of HIV transmission from mother to child based on interviews with mothers. The study noted 7 main reasons for failed PMTCT; 1. Poor application of ARV guidelines 2. Maternal refusal of treatment 3. Early delivery 4. Delayed ANC due to health centre barriers and maternal anxiety of HIV testing 5. Difficulty for the mother in administering AZT to child 6. Lack of understanding of infant feeding.

effect of other barriers. Poor mental health in women living with HIV is an example where psychological state of the individual can mediate decision making. The relationship between barriers can also work in the other direction. Beliefs held by people in a person's environment (social norms and knowledge) as well as socioeconomic and physiological barriers can influence the psychology of the individual. Very few authors have addressed this topic in resource-limited settings, suggesting it would be an area that requires further research.

Physical illness damages the individual's ability to tolerate medication and achieve the best treatment outcomes. In addition, the illness can affect the socioeconomic status of the individual and the household. The potential for decreased income and the pressure on household resources may affect the various facets of access. Many of the households that are affected by HIV are in resource-limited settings and are already economically compromised and physiological barriers can worsen the situation.

Several studies showed a conflict between socioeconomic and social norms and knowledge barriers [27, 28, 33, 34]. In contexts where breastfeeding is the norm and highly valued socially, following previous guidelines to formula feed babies, often exposed women to stigma and fear of HIV status disclosure. This was of course less of a concern in societies where breastfeeding is not dominant or expected. In Botswana and South Africa, the health system gave free infant formula to mothers living with HIV at the clinics, undoubtedly to ensure poverty would not interfere with the implementation of what were at that time the Ministry of Health's guidelines in terms of infant feeding in each country [34, 35]. The measure did, however, create a conflict for many mothers who feared that carrying the tins would lead to undesired HIV status disclosure. In Botswana, some women suggested switching to a voucher modality instead. This is an interesting example where well-targeted measures to reduce poverty-related poor access to services that are meant to enable women to seek health care and comply with recommendations by doctors and nurses can have unintended negative consequences as they interfere with social norms. As a result, women may not take up some of the services offered. In some contexts the mother may overestimate the risk of HIV status disclosure from being seen carrying the infant formula (social norm and knowledge barrier) due to their own internalized fear and subjective perception (psychological barrier).

Another way in which social norms and knowledge barriers overlap with socioeconomic barriers is the area of decision making in the household. From the findings above we note that women in need of care often face issues of stigma from partners and family members who may make decisions which prevent the woman from having access to PMTCT. In some contexts the woman herself may not have

the autonomy to make decisions about her own health, and she depends on a male head of household or another female figure such as a mother in law [25]. This decision making will also apply to the financial resources of the household. The fact that a woman may not have access to the health service is therefore not simply an issue of various social norms but also of how resources are divided. For example, resources such as transport money may actually be available, but not given to the woman who needs PMTCT care due to social norm related issues.

Conclusion

Both quantitative and qualitative papers were reviewed for information on barriers to accessing PMTCT care. The barriers were categorized into four types of demand-side barriers. Socioeconomic and social norm and knowledge barriers are by far the most commonly cited in the literature. Understanding how stigma and beliefs associated with HIV affect whether care is accessed or not, especially in the presence of widespread gender inequality, is very important. They are complemented by physiological barriers, and all three categories can be compounded by patient psychology, a category which appears under-researched in the literature from resource-limited settings.

The review also identified factors that could be helpful in promoting better access to PMTCT services. Promotion of couples being tested together and measures which involve the woman's partner in the referral process were measures cited as ways of sensitizing and reaching out to men who may ultimately decide for the women or are very influential on the woman's decision making process [6]. Women understanding the referral process and being part of HIV support groups are other factors identified as access facilitators [29]. A recent review has found that provision of food can improve adherence and/or treatment completion for HIV care and treatment, ART and TB-DOTS (directly observed therapy) [39]. This indicates that food provision is not only a biological, but also a behavioural intervention, and underscores that unresolved food insecurity can be an impediment to treatment adherence and consequently to good treatment outcomes. Providing food assistance may also have an enabling effect for accessing and adhering to PMTCT care.

In most contexts, economic and social empowerment appears to be critical. Women need the economic means, but also the autonomy to control their health decisions. As a result, poor, young, disempowered women who live far from clinics would appear to be the least likely to access services and show good PMTCT enrolment and outcomes [12, 20].

Information from a range of contexts is required to validate the proposed categorisation. Also, mental health

and psychology as a barrier in resource-limited settings is an area of research that needs greater exploration.

For a more successful PMTCT response, we need to better balance supply and demand side considerations, while also ensuring we have a comprehensive understanding of the multitude, complexity, context dependency and interrelatedness of barriers to accessing the services.

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