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Barriers to Enrollment and Retention in Disease Management Programs

Lujia Zhang; Sebastian Bauhoff*

Abstract

English
Management of chronic diseases has become increasingly important as the global burden of chronic diseases continues to increase. In Latin America there are significant gaps in the provision of chronic care management, with a pressing need to help patients better control their condition. One tool to address gaps in care management is through disease management programs, which include a set of coordinated interventions often with an educational component aimed to improve health outcomes and reduce costs. This paper uses the socio-ecological framework to describe barriers to disease management program enrollment and retention, as well as propose potential interventions to address these barriers. Addressing the many barriers – ranging from the individual factors to larger organizational or policy factors – requires multi-faceted interventions.

Español
La gestión de enfermedades crónicas se ha vuelto cada vez más importante a medida que la carga global de estas enfermedades sigue aumentando. En América Latina existen brechas significativas en el manejo de enfermedades crónicas, con una necesidad urgente de ayudar a los pacientes a controlar mejor su condición. Una herramienta para abordar estas brechas en la gestión de cuidados es a través de programas de manejo de enfermedades, que incluyen un conjunto de intervenciones coordinadas, a menudo con un componente educativo, destinados a mejorar los resultados de salud y reducir los costos. Este documento utiliza el marco socio-ecológico para describir las barreras a la inscripción y retención en programas de manejo de enfermedades, así como para proponer intervenciones potenciales para abordar estas barreras. Abordar la multitud de barreras, que van desde factores individuales hasta factores organizacionales o de política más amplios, requiere intervenciones multifacéticas.

Português
A gestão de doenças crônicas tornou-se cada vez mais importante à medida que a carga global dessas doenças continua a aumentar. Na América Latina, existem lacunas significativas na gestão de doenças crônicas, com uma necessidade urgente de ajudar os pacientes a controlar melhor sua condição. Uma ferramenta para abordar essas lacunas na gestão de cuidados é através de programas de gerenciamento de doenças, que incluem um conjunto de intervenções coordenadas, muitas vezes com um componente educativo, destinadas a melhorar os resultados de saúde e a reduzir os custos. Este documento utiliza o marco socioecológico para descrever as barreiras à inscrição e retenção em programas de gerenciamento de doenças, bem como para propor intervenções potenciais para abordar essas barreiras. Abordar as diferentes barreiras, que vão desde fatores individuais até fatores organizacionais ou de políticas mais amplas,
requer intervenções multifacetadas.

Keywords: Disease management; non-communicable diseases, health systems; Latin America and the Caribbean

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Introduction

Chronic diseases, also known as non-communicable diseases, are a group of conditions typically characterized by a disease long duration that result from a combination of genetic, physiological, environmental, and behavioral factors (WHO, 2023). In Latin America, chronic diseases are the most common cause of death, responsible for more than three-quarters of all deaths (OECD, 2023).

The burden of chronic diseases falls disproportionately on low- and middle-income countries, who often have more limited resources and capacities to address chronic diseases. An estimated 41 million people die from chronic diseases each year, with 77% of deaths occurring in low- and middle-income countries (WHO, 2023). While metabolic risk factors for chronic disease such as blood pressure and cholesterol have been decreasing among high income countries, these risk factors have increased or remained constant in low- and middle-income countries (Kang et al., 2021). The three most common risk factors for chronic diseases in Latin America and the Caribbean are metabolic risk factors (high systolic blood pressure, high fasting plasma glucose, and high body mass index).

Table 1: Top 3 conditions according to their disease burden in LAC in 2019

	Disease burden*	**Share of total disease burden**	**Deaths**	**Share of deaths**
Cardiovascular diseases	20.4 million	12.3 %	962 thousand	26.9 %
Cancers	16.5 million	9.9 %	638 thousand	17.8 %
Diabetes and kidney diseases	13.7 million	8.3 %	395 thousand	11.0 %

Note: Disease burden is measured as healthy life years lost in Disability Adjusted Life Years (DALYs) that capture the total burden of disease: years lived with disability and years of life lost due to premature death. Source: GBD Results tool.

Management of these chronic conditions is often insufficient, with many patients facing gaps in care. In Brazil, where one-third of the adult population is estimated to have hypertension, only 62% of those with hypertension regularly sought care, and 33% had controlled hypertension (Macinko et al., 2018). In Colombia, a study evaluating glycemic control among diabetic adults found only 69% of adults to have a reported HbA1c level, and among those with HbA1c testing, only 52% were below the target threshold of 7% (Ramírez-García et al., 2022). Current delivery models for chronic disease care are only reaching a subset of patients, and effectively managing the condition among an even smaller percentage.

Treatment for chronic disease is often multi-faceted including both direct medical treatment and lifestyle modifications (Cotter et al., 2014; Kastner et al., 2018). One strategy to combat the rising global burden of chronic diseases and better engage patients is through disease management programs. These programs are structured proactive treatment strategies aimed to help individuals manage their disease, reduce avoidable complications, and improve quality of life. Disease management programs have typically targeted costly chronic conditions such as asthma, diabetes, congestive heart failure, coronary heart disease, end-stage renal disease, depression, high-risk pregnancy, hypertension and arthritis (GU Health Policy Institute). Patient participation in these programs has not only led to cost savings and reductions in healthcare resource use, but also measurable improvements in health outcomes (Hisashige, 2013).

Despite the benefits of participating in a disease management program, these programs often struggle with reaching the target population as well as ensuring continued program participation among its enrolled patients. A considerable portion of patients may leave the program before completion, with reported program attrition rates ranging from 5.5% to 77.3% (Fullerton et al., 2012; Inelmen et al., 2005; Verevkina et al., 2014). Given the importance of non-communicable disease burden in Latin America, there is an urgent need for programs aimed to help manage these conditions to enroll and retain patients.

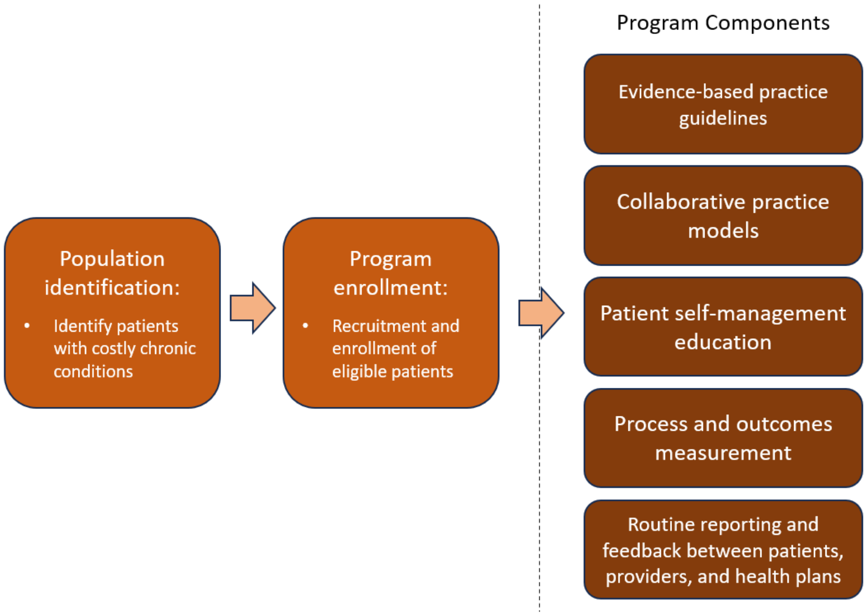
The remainder of this paper focuses on exploring potential barriers to enrollment and retention in disease management programs, as well as interventions to address these barriers. This paper does not provide a comprehensive review of disease management programs or all potential barriers to enrollment and retention. Instead, it presents key insights from the existing literature on programs and prominent barriers in the context of a modified socio-ecological framework. This framework can serve as a tool for health professionals and policy makers to critically evaluate bottleneck points limiting patients from enrolling and remaining in disease management programs.

Overview of Disease Management Programs

The term disease management program encompasses a wide range of health interventions from virtual self-management programs aimed to educate individuals on how to manage their conditions to larger multi-disciplinary teams with physicians, nurses, pharmacists, dietitians, and psychologists providing an individualized treatment plan. The individual components of disease management programs can vary significantly. More comprehensive disease management programs may include patient education, counseling, care coordination, clinical assessment, and medicine evaluation (Moss et al., 2021). Meanwhile, other programs which emphasize self-management may only have an educational or peer-support component (Lorig et al., 2010; Sherifali et al., 2015). The first step of a disease management program typically begins with the **identification of potential participants** who could benefit from the program (Figure 1). Demographic characteristics, medical records, and healthcare use may be used to identify the target population (GU Health Policy Institute). In a diabetes management program, for example, the target population could include individuals with diagnosed diabetes and a blood A1c level ≥ 9 or an emergency department (ED) visit within the last 12 months (Moss et al., 2021).

After the targeted patient population is identified, various recruitment methods may be used to contact and **enroll eligible patients** into the program. In the clinical settings disease management programs may recruit patients through provider recommendation, flyers/brochures in the clinic, or directly contact patients through emails or phone calls. Outside of the clinic, programs may reach potential participants through local media, promotion booths, recruitment events, or advertisements in patient organizations or the community setting.

Figure 1: Typical components in a disease management program



Source: Own depiction with elements from Disease Management Association of America.

Several disease management programs targeting diabetes have been implemented in Latin America with demonstrated improvements (Avilés-Santa et al., 2020). Barcelo et al. (2010), examined an integrated diabetes care intervention in Mexico, which included a structured patient education program, training in foot care, and in-service training for primary care personnel in diabetes management. Compared to the standard of care there were improvements in metabolic control and quality of care. A second study conducted in Brazil evaluating an individualized pharmacotherapeutic care plan and diabetes education found the intervention group to have improvements in diabetes knowledge, medication knowledge, adherence to medication, and correct insulin injection and home blood glucose monitoring technique (Cani et al., 2015).

Example Program I: Group Health Cooperative of South Central Wisconsin – Diabetes Disease Management Program

The Diabetes program by Group Health Cooperative of South Central Wisconsin (GHC-SCW) was developed to educate its members about the disease, teach members how to effectively self-manage the disease, as well as provide support tools and screenings to reduce diabetes related complications and mortality. The program included the following components.

Condition monitoring
Monitoring of hemoglobin A1C, fasting lipid panel, diabetic nephropathy, diabetic retinal eye exam, diabetic medications, lipid lowering agents, hypertension medication, co-morbidities and blood pressure. If monitored indicators are past due, patients are contacted through outreach calls, MyChart messages or postal letters.

Adherence to treatment plants
Patients work with diabetes educators, clinical pharmacists, registered dieticians, nursing staff, and their primary care practitioner to monitor patient adherence in several areas such as weight control, blood pressure control, modification of risk factors, tobacco cessation, medical compliance, and nutritional guidelines.

Medical and behavioral health comorbidities and other health conditions
A collaborative disease management approach is taken to help patients (especially those with multiple co-morbidities), which accounts for individual learning style preferences, cognitive abilities, socioeconomic factors and/or physical limitations.

Health behaviors
Patients are counseled on at risk behaviors to promote healthier lifestyle options and individual counseling may be provided as needed.

Psychosocial issues
Primary care providers along with clinical health educators, nursing staff, case management staff, and behavioral health staff collaborate to identify psychosocial barriers to disease management. Example psychosocial barriers include beliefs and concerns about the conditions and treatment, perceived barriers to meeting treatment requirements, access/transportation barriers to obtaining treatment, cultural considerations, or religious considerations.

Depression screening
The screening instrument PHQ-9 was incorporated into electronic health records to monitor symptoms of depression among diabetic patients.

Encouraging patients to communicate with their practitioners about their health conditions and treatment
A diabetes outreach letter is sent to patients to encourage contact with their practitioner and emphasize the important of communication. Patients can send messages directly to their care team through a secure patient portal within the electronic medical record.

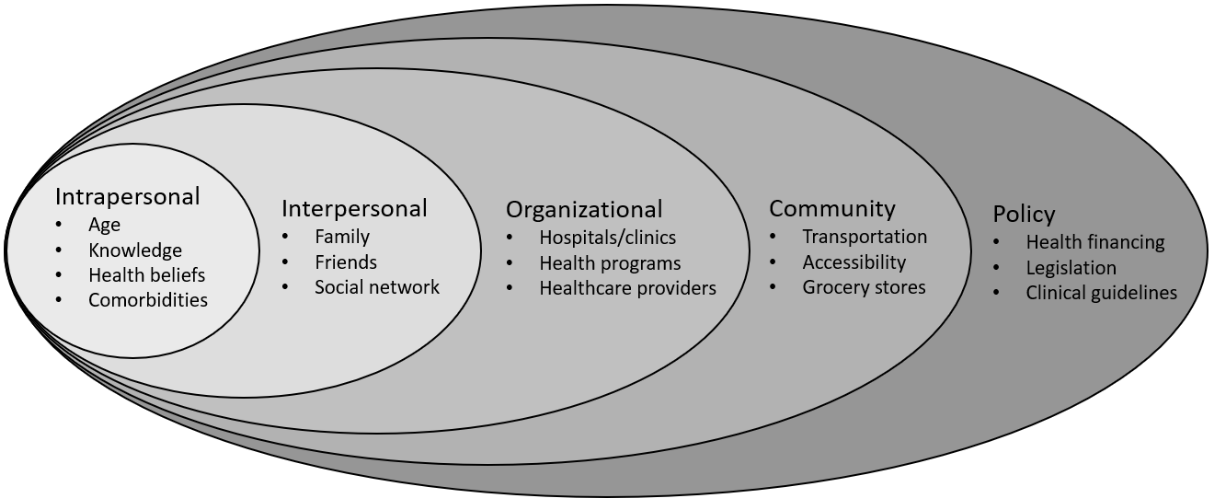
Additional resources external to the organization
Patients are recommended to participate in community resources such as workshops that provide disease management support.

Reference: Group Health Cooperative of South Central Wisconsin (Diabetes Disease Management Program, 2017).

Conceptual framework for understanding barriers to enrollment and retention in disease management programs

This paper uses the socio-ecological framework, a model frequently used in public health research to conceptualize health behavior, to describe barriers to disease management program enrollment and retention (Figure 2). Unlike behavioral models which focus on individual characteristics and proximal social influences, the ecological model also accounts for broader community, organizational and policy factors impacting health behavior, allowing for the integration of multiple theories (Sallis et al., 2008).

Figure 2: Socio-ecological framework



Source: Own depiction of socio-ecological framework.

Several adaptations of the ecological model have been made, however they generally consist of the following levels: individual, interpersonal, organizational, community, and policy (Kennedy et al., 2021). At the first level of the model there are **individual** factors, which include biological and personal characteristics such as age, gender, race, education, knowledge, or attitudes. The **interpersonal** level encompasses interactions with other people such as family members or friends which can influence an individual's behavior and experiences. Then at the **organizational** level there are institutions like health centers, workplaces as well as both formal and informal structures. The **community** level includes broader social relationships, norms, and settings. Finally, at the **policy** level, there are policies, laws and other regulatory measures which may occur at a local, national, or even global level.

Individual Factors

Several studies have evaluated the demographic characteristics of individuals enrolling in disease management programs. Differences in enrollment rates across **age, gender, and race** have been documented. In Germany, enrollment rates into coronary heart disease and diabetes disease management programs have been found to be higher among males and to be generally increasing with age (Kauhl et al., 2022; Röttger et al., 2017). As individuals reach retirement age, they face a lower opportunity cost of time and typically have more flexibility in their schedule to attend disease management programs. However, at the same time, older age is associated with poorer cognitive function and a greater a greater number of comorbidities, which can make participation in the program more challenging or less of a priority. A few studies have also indicated that age is associated with attrition rates. Younger individuals before retirement age have been found to be more likely to drop out, however, after retirement the association is less clear (Beishuizen et al., 2017; Fullerton et al., 2012; Verevkina et al., 2014).

In the United States differences in enrollment rates have been documented across racial groups. For example, Black Medicaid beneficiaries with Alzheimer's disease and related dementias were found to have a 9% lower odds of enrollment into the Medicare Medication Therapy management program[2] compared to White beneficiaries (Browning et al., 2022). The differences in enrollment rates across racial groups could be due to a variety of factors such as differential access to resources, social support or differences in treatment by healthcare providers.

Among studies examining program attrition, differences in gender and race have generally been found to not be significantly associated with attrition (Fullerton et al., 2012; Gucciardi et al., 2008; Lorig et al., 2010; Verevkina et al., 2014).

One of the most frequently noted individual factors influencing enrollment into disease management programs and program attrition is an **individual's health beliefs, both in terms of perceived disease severity and self-efficacy**. An individual's perceived need could depend on factors such as their knowledge regarding their disease and potential side effects, their knowledge about disease management programs, or the saliency of their symptoms (Flynn et al., 2013; Slauson-Blevins et al., 2013). Conditions such as hypertension, which have little to no symptoms are often underweighted (Osterberg & Blaschke, 2005). Knowledge and symptom salience can similarly influence an individual's self-efficacy. Greater knowledge regarding how to manage one's condition increases one's self efficacy and decreases the need for the additional support provided by disease management services. Meanwhile, less salient symptoms can lead the individual to believe their health condition is properly managed by themselves.

Enrollment rates have been shown to be lower among individuals who perceived their disease to be less severe or that they had the self-efficacy to manage their condition without the program (Jackson et al., 2012). Individuals who declined participation in a diabetes self-management program frequently cited they had no need for the program, as they had sufficient knowledge about their condition and how to manage it (Coningsby et al., 2022). Attrition rates are similarly higher among individuals who perceive their condition to be less severe and have greater confidence in their own knowledge and ability to manage the condition (Gucciardi et al., 2008; Sharifi et al., 2022; Sohanpal et al., 2012).

Another key factor affecting patient decisions for disease management at the individual level is the **presence of comorbidities**. Most disease management programs focus on a single chronic condition. Having multiple comorbidities, especially disabling comorbidities, can create physical challenges to participating in a program (Fullerton et al., 2012; Wermeling et al., 2014). For example, comorbidities such as debilitating back or leg pain can make travel to a disease management program challenging (Sharifi et al., 2022). Second, the presence of multiple comorbidities can influence how an individual prioritizes disease management for different conditions (Flynn et al., 2013; Jackson et al., 2012; Sharifi et al., 2022). When disease management programs target one only condition, and individuals have multiple comorbidities, the

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[2] The Medicare Medication Therapy management program is a group of services aimed at reducing drug-related risks, increasing medication awareness, and improving medication adherence.

benefits from the program may seem less valuable (Jackson et al., 2012). For example, a study evaluating enrollment to a hypertension management program found that having multiple comorbidities pushed blood pressure control lower on the priority list and lowered enrollment in the hypertension program (Flynn et al., 2013).

Interpersonal factors

At the interpersonal level enrollment into disease management programs can vary with the **degree of dependence on family members or friends for support**. Family members can play an important role in providing emotional support and assistance to better manage the disease (Coventry et al., 2014). Family members can also assist in disease management in a variety of ways, such as helping to prepare meals, providing transportation, relaying information at medical appointments, or reminding patients to take their medication (Flynn et al., 2013). The lack of ability or willingness of family members and friends to assist can make participation in a disease management program more challenging.

Family dynamics, specifically an individual's roles and responsibilities in the family can also impact individuals' abilities to participate in these programs. The responsibilities an individual has at the family level can influence their ability and willingness to participate in disease management programs. For example, in some families women take on extensive responsibilities such as taking care of their children, cooking, and cleaning, which prevent them from having the time to take care of themselves (Sharifi et al., 2022). These barriers can play a bigger role for chronic conditions affecting younger or middle-aged working age adults, as this group is more likely to have young children, jobs, or other responsibilities limiting their available time.

Another important factor at the interpersonal level is **culture**. An individual's diet, lifestyle, and stress management are all important factors in disease management that are influenced by one's culture. Cultural differences can influence the perceptions of symptoms, emotional state, and beliefs regarding appropriate treatment (Shaw et al., 2009). These differences can make communicating with physicians as well as understanding or processing information more challenging (Lambert et al., 2021). Additionally, when disease management counseling is incompatible with an individual's culture, there may be a greater reluctance to participate. Wermeling et al. (2014), conducted a qualitative interview among diabetic patients receiving lifestyle counseling, and found incompatibility between dietary recommendations and patient's eating culture to be a major factor limiting program adherence. In many cultures there is a social component to cooking and eating, and food may be an important part of one's cultural identity. The adaptability of lifestyle modifications to different cultures can influence patient acceptance of the program.

The relationship between patients and their physicians can also play an important role in disease management. The level of physician-patient trust is associated with patient satisfaction and compliance towards disease management (Mascarenhas et al., 2006). Lack of continuity in care among physicians and poor communication between physicians and patients can lead to lower levels of trust. Patients who have a regular place of care and doctor, or have had their regular physician for 6 or more years have been shown to have higher levels of trust in their doctors (Mainous et al., 2001).

Organizational factors

At the organizational level, the structure of a disease management program can also influence enrollment and retention. Present bias among patients can result in patients placing larger weights on small organizational inconveniences than long term benefits. One prevalent factor influencing the ability of patients to participate was the **program scheduling**. Conflicting hours of operation with work or childcare can make attending disease management programs more challenging. Committing to attending regular program sessions is especially difficult for individuals working shifts or irregular hours (Coningsby et al., 2022). An interview of individuals attending a diabetes education center found inconvenient hours that conflicted with work schedules to be the most frequently cited reason for attrition (Gucciardi et al., 2008). The likelihood of dropping out of programs has also been found to be lower for those attending weekend sessions than those attending midday or evening sessions during the work week (Verevkina et al., 2014). While evening sessions may be less likely to conflict with work schedules, patients may have greater time costs having to travel during rush hour (Sharifi et al., 2022). Other organizational factors, such as long clinic wait times which increase the time costs for patients can also serve as barriers to participation (Flynn et al., 2013).

Healthcare providers themselves also play an important role in encouraging patients to participate in disease management programs. Patients often rely on healthcare providers to inform them of health implications, motivate them to take appropriate action, and guide them on the appropriate next steps (Wermeling et al., 2014). For example, the rates of enrollment in disease management programs are higher when programs are advertised through direct patient referral rather than through mail, telephone or posters/fliers (Beaton et al., 2010). Poor communication skills among healthcare providers and gaps in literacy levels between patients and healthcare workers can serve as barriers to program enrollment (Sharifi et al., 2022). Effective communication between healthcare workers and patients can help patients better understand the severity of their health condition and value of disease management programs. **Clear communication and guidance** are especially important for individuals from lower socio-economic communities, who often place an even greater reliance on health care professionals for disease management (Coventry et al., 2014).

Community factors

At the community level, **accessibility** is a prominent barrier to disease management program enrollment and continued attendance. Cost of transportation, distance, and travel time can all impact an individual’s decision to participate in a disease management program. Individuals from rural communities or living in areas with lower socioeconomic typically have less access to both public and private transportation, and longer travel distances (Coventry et al., 2014; Heckman et al., 1998). The impact transportation factors can have on accessing care is also dependent on an individual’s health status. For example, individuals with leg problems, severe back pain, amputation, arthritis, or other physically debilitating conditions may find it difficult to travel using public transportation and may require other transportation methods (Coningsby et al., 2022).

Within a community, the **availability and ease of accessing various supportive resources** can also facilitate disease management. For example, one study evaluating non-participation in a diabetes management program found the lack of facilities such as parking or elevators discouraged program attendance (Sharifi et al., 2022). Having resources such as grocery stores for fresh produce, parks for physical exercise, or facilities to monitor blood pressure can all impact individual's capability to make lifestyle modifications and actively manage their condition (Flynn et al., 2013). The availability of educational resources in the community can also influence patient awareness and knowledge about their condition.

Policy factors

It is estimated that one in three adults have more than one chronic condition (Marengoni et al., 2011). With the high prevalence of multimorbidity's, **inadequate clinical guidelines** that target only one condition and do not consider the patient's socio-personal context and personal preferences can lead to poor treatment adherence (Wyatt et al., 2014). If patients are unable to implement guidelines, provider recommendations will have little effect. Narrow clinical guidelines can also post as a challenge to physicians when managing multiple conditions with potentially conflicting guidelines; physicians may deviate from guidelines, choosing to prioritize certain conditions and postpone care to others (Wyatt et al., 2014).

At a health system level, **fragmentation of the healthcare system, lack of communication across health care providers, and poor communication between different levels of the health system** can serve as a barrier to chronic disease management. Fragmentation of care is particularly important for patients with comorbidities, who often seek care from multiple specialists. The lack of integration of medical records in health systems can result in poor inter-provider communication, medication reconciliation errors and other patient safety errors that limit a patient's ability to be informed and engaged in disease management (Sloan et al., 2020). Fragmentation of care can also lead to inefficiencies such as repetitive testing that place a greater burden on patients. Not only poor inter-provider communication, but poor communication across different levels of the health system can negatively impact health management. Policy makers may define guidelines and protocols for disease management; however, these guidelines and tools need to be practical and clearly communicated to healthcare providers to be effectively implemented

Another policy level barrier is the **financing and payment of disease management programs**. In Germany, the introduction of disease management programs into the social health insurance scheme in 2002 meant that access to these programs were covered and paid for by insurance (Busse, 2004). Meanwhile, in the United States where health insurance coverage is not uniform, people may be reluctant to participate in the program if they are don't have private health insurance coverage or are not eligible for Medicaid (Kennedy et al., 2021). Policy decisions regarding who pays for the program and who is covered have a direct impact on the cost barriers that patients may face.

The following box summarizes findings from a qualitative study on barriers to effective disease management for type 2 diabetics in Colombia (Tejedor Bonilla et al., 2024).

Example program II: Barriers to effective disease management – Type 2 diabetes in Colombia

As many countries in Latin American and the Caribbean, Colombia struggles to manage a high and growing burden of disease for type 2 diabetes. In 2018/2019, only about two-thirds of diagnosed diabetics had a reported blood sugar test and about half of these had achieved glycemic control. A recent qualitative study supported by IDB identified several barriers across different stakeholders and parts of the care management process. The following table highlights preliminary insights of this study.

Stage	Individual/patient	Health professional	Health plan	Provider
I. Identification of the population at risk	Cultural, risk minimization	Low training and risk identification	No differential payment	No effective demand
II.A. Entry point - Outpatient consultation	Late Consultation Lack of knowledge of warning signs and symptoms Lack of knowledge of the disease	Lack of knowledge in diagnosis	Failures in the articulation of the offer	Lack of training Service fragmentation Lack of timeliness in the offering program Limited consultation time (15-20 min)
II.B. Entry point - Emergency and hospital care		Lack of knowledge of the existence of the program		Failure to provide training on the care program
III. Enrollment in program	Denial of the diagnosis Minimizing risk Rejection of the program Lack of time to receive care	Lack of knowledge of the route Lack of personalized enrollment	Fragmentation of supply Fragmented Dispensing Contract Extensive paperwork	Staff training Assignment of patients due to staff availability, leading to lost continuity of follow-up by the primary care professional
IV. Start of the program	Minimizing the risk of the disease Lack of support from the social nucleus (family, partner, children, work)	Fragmentation of the interdisciplinary group Event-based care rather than person-based care	Fragmentation of supply and insufficient supply	Lack of timeliness in the offering program Weakness in the training of professionals Limited consultation times (20 min)
V. Follow-up	Disinterest and exit from the Program Low adherence Lack of support from the social nucleus (family, partner, children, work)	Weakness in training Low satisfaction	Discontinuity in contracts with the delivery network	Cohort and non-person follow-up Weakness in incentives for professionals Limited consultation time (15-20 min)

Reference: Tejedor Bonilla, M. F., Benavidez Velandia, N. L., Bauhoff, S., & Castro Vargas, S. (2024). Adopción y percepciones de la Telemedicina en el cuidado de enfermedades crónicas: Diabetes Mellitus tipo II en Colombia. Nota Técnica BID.

Addressing barriers to enrollment

From the health systems perspective, there are various interventions that can be implemented to reduce barriers to enrollment and retention in these disease management programs. Potential interventions can target barriers across the different levels in the socio-ecological framework (Table 2).

Table 2: Interventions from the health system perspective to increase enrollment and retention in disease management programs

	Key Barriers to Care	Example Interventions
Individual Level	Low perceived disease severity or need for disease management programs	• Providing patients with information on the benefits of participating in a disease management program • Providing incentives to patients for enrolling
	Patients facing multiple comorbidities	• Offering integrated disease management programs targeted towards multiple conditions to patients with comorbidities
Interpersonal level	Family lifestyle/culture incompatibility with care interventions	• Offering alternative program interventions based on patient lifestyle preferences and culture (e.g. different dietary recommendations based on different eating cultures)
Community level	Lack of transportation; Lack of community support or stigmas against the disease	• Providing transportation subsidies, and/or offering transportation to health facilities • Offering telehealth or virtual options when possible • Community education events
Organization level	Inconvenient program hours	• Offering weekend program/appointment hours, telehealth options, or asynchronous options
	Poor communication between providers/healthcare organizations and patients	• Recruiting patients through direct referral instead of email or phone calls • Providing patients with detailed program information on program components and what to expect • Sending patient reminders for appointments, medication fills etc.
Policy level	Fragmentation of care	• Increasing patient data sharing through electronic health records • Aligning provider incentives with patient needs

Individual level

A key barrier affecting disease management at the individual level is health beliefs, especially beliefs regarding the potential benefits of participating in a disease management program. When individuals have imperfect information regarding the potential benefits of a program or the costs/severity of their health condition, they may choose not to enroll in the program even when the benefits are greater than the cost. In cases where patients do not fully understand the benefits of participating in a disease management program, educating patients on their health condition can help individuals better understand the value of such a program and enroll more patients who can benefit from enrollment. This can be especially valuable for disease management programs addressing chronic conditions with less salient symptoms where patients are more likely to underweight their severity.

Several studies have shown that **health education** can increase the uptake of public health or medical interventions. Agide et al. (Agide et al., 2018) conducted a systematic review evaluating the effectiveness of health education interventions to increase cervical cancer uptake and found screening uptake to increase from a variety of educational tools, including phone calls, educational videos, lectures, radio/media broadcasts. Educational interventions have also been shown to be effective at increasing vaccine uptake. Wong et al. (2016) found a brief 10-minute vaccine information session during antenatal visits to increase the odds of getting the influenza vaccine by 2.45.

The use of educational tools may not only serve as an effective method to increase enrollment into disease management programs, but also improve program adherence. Verbal education has been shown to increase medication adherence for hypertension patients, with a greater frequency of communication associated with better adherence (Ampofo et al., 2020). Similarly in diabetes management, educational interventions delivered both in person and over the phone have led to improvements in medication adherence and clinical outcomes (Zullig et al., 2015).

While patient education focuses helping patients understand the benefits of the program, an alternative method is to further increase the benefits of participating in a disease management program. One example of this is through **providing patients with incentives**. Monetary incentives have been used to both increase enrollment and attendance in disease management programs. Alexander et al. (2008), examined a combination of different enrollment and retention incentives for an online health program; finding the optimal incentive in their study setting to be a small prepaid incentive combined with a slightly larger enrollment incentive, which increased enrollment by 10%, and retention by 71%. In weight management programs, the use of monetary incentives through program cost reimbursements have led to both better attendance and greater weight loss (Butsch et al., 2007; Hubbert et al., 2003). Other forms of incentives, such as free educational materials, could also serve as a potential tool to increase attendance or enrollment. A qualitative interview of non-participants in a diabetes self-management program, noted rewards such as educational books and CDs for continued participation to be an incentive factor that could also improve the effectiveness of instruction (Sharifi et al., 2022).

Another method to increase the program benefits for individuals is through **providing integrated disease management programs** which address multiple conditions and minimize the patient burden in coordinating. Individuals who chose not to participate in disease-specific management programs often noted having other health conditions, and that simply focusing on one of their health conditions would provide little improvements to health (Jackson et al., 2012). An integrated care model was implemented in Nova Scotia to improve health outcomes for patients with multimorbidity (Sampalli et al., 2012). The integrated model included coordination of care across an integrated multidisciplinary care team, a medical management scheme to facilitates patient care across the spectrum of diagnoses and symptom profile, care coordination appointments, and behavioral management. Results from a small sample of patients indicated improvements in overall health and patient fatigue.

Interpersonal level

When developing a **treatment plan**, it is important for healthcare providers to consider the patient’s family, social and cultural influences. In the context of diabetes care, insulin remains underutilized despite its effectiveness and guideline recommendations (Rebolledo & Arellano, 2016). Rebolledo and Arellano (2016) found lack of family support, as well as negative social perceptions towards insulin among certain cultures to limit insulin use. Depending on a patient's family or cultural background, providers may have to spend more time educating patients on the importance of certain medications, and/or switch to medication options that the patient can better adhere to. For chronic conditions requiring lifestyle changes, such as dietary modifications, suggestions for changes should account for the patients eating culture. Diet modifications to a "western diet", for example, may be unappealing for patients who are used to eating a traditional south-Asian diet and make dietary changes more challenging (Iqbal, 2023).

Community level

Transportation availability and costs serve as a major barrier to disease management, especially among lower income adults. Starbird et al. (2019) conducted a literature review to evaluate a variety of interventions aimed at **reducing transportation barriers** among people with chronic diseases, through methods such bus passes, taxi vouchers, shuttle services, and connecting patients to transportation services. While nearly all interventions led to an increase in healthcare utilization, the effectiveness varied by population characteristics. For example, among older adults, taxi vouchers and free shuttle services were much more effective at linking patients to care than bus passes, which is consistent with older adults using public transportation at a lower rate (Hughes, 2017). The feasibility and effectiveness of an intervention will vary by the disease management program and targeted patient population. Certain interventions such as taxi vouchers or shuttle services may be more feasible for less frequent visits, however, may be too costly for programs requiring regular visits. Meanwhile providing bus passes will only be useful if the target population has access to public transportation and is willing to use this method.

Alternatively, the use of **telehealth or mobile health programs** can help eliminate transportation costs as well as reduce productivity losses. In the United States the use of telehealth among nonelderly cancer patients for cancer care was estimated to generate cost savings in the range of $147 to $186 per visit from reduced productivity losses and travel costs (Patel et al., 2023). Telehealth has also been found to reduce barriers related to cost and access in low-resource settings. Sayani et al. (2019) evaluated the introduction chronic disease management through telemedicine in remote regions of Afghanistan, Pakistan, Tajikistan, and the Kyrgyz Republic, and estimated travel cost savings to be between $28 to $454 per capita. In addition to reducing patient costs, telehealth can also improve disease management through other mechanisms such as allowing for more frequent monitoring or making it easier for family members to participate in visits (Corbett et al., 2020).

Community events, and the use of **community-based health workers (CBHW)** can also serve as a source of support for disease management and work synergistically with the program. CBHW's can serve as a bridge between the health system and the communities they work in, delivering both medical and nonmedical services. For example, educational events in the community can be implemented to reduce stigma, false perceptions about the condition and raise general awareness regarding disease management. A systematic review of a wide range of CBHW interventions including education, counseling, navigation assistance, case management, and social services found these interventions to be effective in promoting CVD risk reduction, cancer screening and cognitive function (Kim et al., 2016).

Organizational level

Disease management programs use a **variety of recruitment methods**, some of the more common methods include provider recommendation, media/advertising, and letters or phone calls (Horrell & Kneipp, 2017). The effectiveness of these strategies at recruiting participants can vary. Goldman et al. (2019), evaluated the effectiveness of different recruitment strategies to enroll diabetic patients into a lifestyle intervention. Direct referral of patients into a disease management program through physicians led to a 27% enrollment rate, while mail/telephone from patient registries led to an enrollment rate of 2% or less, and the use of media/advertising through posters and fliers at clinics was ineffective. Direct referral through a physician may increase the and an individual's perceived need for the disease management program. Another study compared the use of mail only vs mail and phone calls to recruit health plan members identified with diabetes to participate in a diabetes education clinical trial (Beaton et al., 2010). The use of mail only led to a 4.2% enrollment rate, the use of mail and phone calls to non-responders led to an 8.4% enrollment rate, and the use of mail and non-selective phone calls to all patients led to a 7.9% enrollment rate.

While the method of recruitment can influence enrollment rates, **a trusted messenger** themselves can also play an important role. Individuals place different weights on information they receive depending on who it comes from (Vlaev et al., 2016). How an individual feels about the messenger, or their perceived authority of the messenger can all influence how effectively the message is communicated (Webb & Sheeran, 2006). For example, 76% of parents reported endorsing a lot of trust in their children's doctor for vaccine safety information compared to 23% for government officials and 15% for family and friends (MacArthur, 2014). Having physicians place a stronger emphasis on the importance of participating in a disease management program could help improve enrollment rates. A study evaluating medical, psychosocial, and demographic predictors of participation in an outpatient cardiac rehabilitation program found the strength of the provider's recommendation to be the most powerful predictor of participation (Ades et al., 1992).

Disease management programs can also help to reduce the burden on patients by providing more **detailed program information and reminders**. Patients may also be present biased, such that the immediate costs they face such as cost sharing, hassle costs, scheduling appointments, or filling prescriptions are overweighted (Newhouse, 2006; O'Donoghue & Rabin, 1999). Calls from clinics or hospitals reminding patients of upcoming appointments or prescription refills can help facilitate disease management (Flynn et al., 2013). Hardy et al. (2001), found non-attendance rates to be lower when diabetes clinics provided detailed information to patients on where to go for appointments, what to expect, and providing reminder calls. Providing additional information regarding program scheduling can help patients minimize scheduling frictions. For example, one interviewee with mobility constraints noted that a reason for not attending a diabetes education program was not knowing when the program would end made it difficult for them to schedule a pick-up time with their driver (Coningsby et al., 2022).Using physician referrals as a tool to increase participation, a second study evaluated the impact of educating physicians about the benefits of cardiac rehabilitation programs and setting up a referral system on patient participation in cardiac rehabilitation. The intervention led to an increase in physician referrals from 18% to 89%, and a 32.8% increase in patient participation (Dahhan et al., 2015).

Policy level

Fragmentation of healthcare serves as a barrier to accessing high quality healthcare among chronic disease patients who often require a multidisciplinary care team. Care fragmentation not only increases the patient burden for care management but has also been adversely associated with hospital use, risk of comorbidities and healthcare costs among adults with chronic conditions (Joo, 2023). One method to **reduce fragmentation of care** is through sharing data and improving care coordination. Policy initiatives such as the Medicare and Medicaid HER Incentive program have been implemented in the US to encourage the implementation of certified electronic health record technology that promotes the interoperability and exchange of healthcare data. Policymakers can provide financial benefits or reimbursements to encourage patient data sharing. Another method to reduce care fragmentation is through aligning provider incentives with patient needs for care. The use of payment models such as fee-for-service does not incentivize quality and can discourage teamwork as payments are based on actions of individual providers. Instead, provider payment methods should focus on rewarding high quality and efficient care. Payments for episodes of care, for example, discourage the inefficient use of resources and incentivize providers to integrate their offerings (Hyman, 2010).

Conclusion

There are a multitude of barriers to enrollment and retention in disease management programs ranging from individual behavioral factors to broader societal factors. The list above should not be used as a comprehensive list, but rather a summary of common factors to consider when evaluating potential barriers to program enrollment and retention. Several of the studies cited in this paper evaluating disease management programs were over 10 years old, and there were few studies from Latin America and the Caribbean, further highlighting the need for understanding how to effectively enroll and retain patients in the modern Latin American and Caribbean context. The specific barriers faced by a patient population are often context specific and can vary depending on the population characteristics and disease management program components. It is crucial for disease management programs to understand the barriers most prominent in the target population.

An understanding of barriers among the target population can then help guide the design of disease management program and the use of appropriate interventions aimed at improving enrollment and retention. The individual interventions targeting different levels which were included as example interventions target focus only one specific barrier. Patients may face multiple barriers to participating in disease management programs, thus effective engagement with patients may require a multi-faceted approach combining interventions occurring at different levels.

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