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Adherence to Pulmonary Rehabilitation in COPD: A Qualitative Exploration of Patient Perspectives on Barriers and Facilitators

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Abstract

Purpose: Adherence to pulmonary rehabilitation (PR) is low. This qualitative study used the PRECEDE model to identify predisposing (intrapersonal), reinforcing (interpersonal), and enabling (structural) factors acting as barriers or facilitators of adherence to PR, and elicit recommendations for solutions from COPD patients.

Methods: Focus groups with COPD patients who had attended PR in the past year were conducted. Sessions were recorded, transcribed verbatim, and coded independently by two coders, who then jointly decided on the final coding scheme. Data were summarized across groups, and analysis used a thematic approach with constant comparative method to generate categories.

Results: Five focus groups with 24 participants were conducted. Participants, mean age 62 yr, were 54% male, 67% Black. More than half had annual income less than \$20,000, 17% were current smokers, and 54% had low adherence (less than 35% of prescribed PR sessions). The most prominent barriers included physical ailments and lack of motivation (intrapersonal), no support system (interpersonal), transportation difficulties, and financial burden (structural). The most prominent facilitators included health improvement, personal determination (intrapersonal), support from peers, family, and friends (interpersonal), and program features such as friendly staff and educational component of sessions (structural). Proposed solutions included incentives to maintain motivation, tobacco cessation support (intrapersonal), educating the entire family (interpersonal), transportation assistance, flexible program scheduling, and financial assistance (structural).

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Conclusion: Health limitations, social support, transportation and financial difficulties, and program features impact patients' ability to attend PR. Interventions addressing these interpersonal, intrapersonal, and structural barriers are needed to facilitate adherence to PR.

CONDENSED ABSTRACT

This qualitative study identified barriers and facilitators to pulmonary rehabilitation from the perspective of COPD patients. Health limitations, social support, transportation, financial difficulties, and program features impact ability of patients to attend sessions. Solutions included motivational incentives, tobacco cessation support, educating the entire family, transportation services, flexible scheduling, and financial assistance.

Keywords

adherence; pulmonary rehabilitation; COPD; qualitative research; patient perspectives

Pulmonary rehabilitation (PR), recommended in international guidelines for management of chronic obstructive pulmonary disease (COPD),¹ has been associated with improvements in quality of life, dyspnea, and exercise tolerance and a decrease in exacerbations and hospitalizations.^{2–5} Despite demonstrated benefits, uptake of PR is low.^{6–8} Research has focused on clinical (oxygen use, shuttle walking distance, lung function, exacerbations, hospitalizations, depression) and demographic (sex, smoking status, marital status) predictors of PR completion.^{6,9,10} Socioeconomic disadvantage has also been identified as a correlate of adherence.¹¹ Expanding on the results of a quantitative study of adherence to PR,¹² this qualitative research explored barriers and facilitators of adherence to PR using focus groups with COPD patients to identify potential adherence-promoting strategies.

METHODS

Theoretical Framework

Barriers and facilitators to PR exist on multiple levels, including individual, interpersonal, and health system.¹³ Therefore our analysis was guided by the PRECEDE model,¹⁴ which identifies predisposing (intrapersonal), reinforcing (interpersonal), and enabling (structural) factors relevant to health behaviors and programs. Predisposing factors involve the knowledge, beliefs, and values affecting decision-making. Reinforcing factors include the influence of family, friends, and others. Enabling factors include the socioeconomic, organizational, and policy factors influencing a health behavior. The PRECEDE model has been used successfully in interventions for HPV vaccination uptake,¹⁵ asthma self-management,¹⁶ and diabetes self-care,¹⁷ among others.

Study Design

This study constituted the qualitative phase of a mixed methods investigation with sequential explanatory design,^{18,19} whereby the collection and analysis of qualitative data followed the collection and analysis of quantitative data to increase the interpretability of results.²⁰ The quantitative phase reported associations between social determinants and adherence to PR. Relative to high adherence (>85% of prescribed PR), moderate adherence (35–85% of

prescribed PR) was associated with neighborhood-level socioeconomic disadvantage, including poverty, public assistance, households without vehicles, cost burden, unemployment, and minority population; while low adherence (<35% of prescribed PR) was associated with current smoking and poor functional health.¹² The qualitative phase explored these associations in depth. Interview questions were guided by the PRECEDE model, asking about the role of intrapersonal factors (knowledge, beliefs, health status), interpersonal factors (family, friends), and enabling factors (financial considerations, transportation, and program features) for completion of PR.

Data Collection

The study population consisted of COPD patients who had attended PR in the previous 12 mo (n = 174). After excluding deceased and out-of-state patients, the final sample included 166 individuals. An adherence score was assigned to each individual based on the proportion of completed-to-prescribed PR sessions as described in the quantitative phase:¹² high (>85% of prescribed), moderate (35–85% of prescribed), and low (<35% of prescribed). We aimed to conduct 5 focus groups with diverse representation of adherence levels. Therefore, we divided the sample (n = 166) into 5 source groups (n = 33 each with one n = 34) using the following scheme: from the low-adherence pool, every 5th individual was assigned to a source group, starting with group 1, until all were assigned; from the moderate-adherence pool, every 4th individual was similarly assigned; from the high-adherence pool, every 3rd individual was similarly assigned. A focus group was then recruited from within its respective source group. Contact was attempted with all 166 individuals. Focus group participants signed an informed consent and received a \$50 gift card. A semistructured guide (Table 1) was used to prompt participants about challenges to attending PR, facilitators of completing PR, and strategies to help patients attend PR. Focus group sessions were audio-recorded, transcribed verbatim, and de-identified for analysis. The study was approved by the Institutional Review Board of the University of Alabama at Birmingham (Protocol X160907008).

Data Analysis

Data analysis used a thematic approach.²¹ A constant comparative method^{22,23} was employed to generate categories, patterns, and themes. Transcriptions were coded independently by 2 team members, then codes were discussed by the team, and the final coding scheme was decided jointly. Discussions contributed to the iterative data analysis and acted as respondent validation,²⁴ helping achieve trustworthiness through investigator triangulation.²⁵ Inter-rater agreement was assessed with Cohen's Kappa (κ) with $\kappa = 0.81$ considered to be near perfect agreement.²⁶ Analyses were conducted with NVivo 11 (QSR International).

RESULTS

Figure 1 presents a STROBE (STrengthening the Reporting of OBServational studies in Epidemiology) diagram of study participants. A total of 24 individuals participated in 5 focus groups (n = 6, 5, 4, 4, 5 persons/group, respectively). The characteristics of participants are presented in Table 2. Most participants were Black, with high-school

education or less, household income <\$20,000, and low PR adherence (<35% of prescribed PR). Focus group discussions identified barriers and facilitators to PR and recommended solutions. The themes from high-frequency codes are presented in Table 3.

Barriers to Adherence

Predisposing (Intrapersonal) Barriers—The most frequent barrier was health limitations. Participants indicated that pain, lack of mobility, and physical ailments make it very difficult to attend PR sessions.

“I have arthritis, gout, and all combined in one. [...]”

“I really don’t like getting on the Interstate, because my—I never know when my bronchitis will act up and my sugar most definitely acts up.”

Disease complications were also a prominent theme when discussing barriers to PR.

“I didn’t complete. [...] And the first time that I was in it, I had pneumonia. And I really have—I have pneumonia a lot [...]”

In addition to physical limitations, participants spoke of lack of motivation as a significant barrier to attending sessions:

“Like me for instance, you know the devil get in me some days, you know, some days I just don’t wanna get up. Especially on Mondays.”

Reinforcing (Interpersonal) Barriers—Participants described how lack of social and emotional support interferes with session completion.

“I really miss my wife cuz she attended all the sessions. [...] You gotta have one that will be there for you.”

Enabling (Structural) Barriers—Most participants discussed transportation as a major barrier to attending PR. This theme included topics such as not having a car and having to rely on buses to get to sessions.

“A lotta people have problems with transportation. I’m havin’ it now. Because I ride the VIP bus and you can tell them I hafta be there at 9:15, and they don’t be on time. Sometime(s) they don’t get me to 10:30.”

The next most discussed barrier was financial struggles, including copays, costs not covered by health insurance, or lack of health insurance. Respondents described cost burden as a major hindrance to PR.

“You know, you have to come out your pocket for the copayments and all this. Sometimes I have prescriptions that run like \$100, \$150, you know. That’s every month. [...] I have to see 3 or 4 doctors a month, you know. Sometimes, just \$500 or \$600 a month be just out of my pocket.”

Facilitators of Adherence

Participants were asked what helped their efforts to complete PR sessions. Again, predisposing (intrapersonal), reinforcing (interpersonal), and enabling (structural) stimuli were identified.

Predisposing (Intrapersonal) Facilitators—Seeing their health improve was the most important facilitator of adherence to PR. Participants felt motivated to complete their sessions when they saw that they could breathe better, walk more, or lost weight. Most everyone discussed the encouragement they felt when their symptoms improved, and these experiences served as powerful facilitators of treatment completion.

“Improving on my numbers. I hated the treadmill. But I’m up to a mile, and one-third of it without any oxygen. [...] I’m looking at 40-something pounds that I’ve lost.”

Personal determination was discussed as an internal facilitator of adherence. Participants stated that when an individual had the will to complete their sessions they did not allow any barriers to interfere.

“Well, it’s just a mind game. If you feel like you need to do this, you’ll go and do it. But if you say I ain’t gonna do it, it ain’t gonna bother me none, you know, then you’re the one that’s losin’. [...]”

Although determination was viewed mostly as an intrinsic quality of the individual (*“It’s in the person”*), some participants recognized that it can be externally motivated, for example by the desire to achieve a goal, such as the ability to spend time with one’s grandchildren or travel.

“For me it was the determination [...] my dream is to be able to travel still. And it was frustrating sometimes but I was just determined.”

Reinforcing (interpersonal) facilitators—Participants underscored the importance of social support and emotional encouragement, and how it motivated them to remain in the program. The fellowship of and accountability to peers in the program were key to completing treatment.

“Actually, there’s some camaraderie there. [...] I see what you’re doing today, and I look forward to being able to do that maybe. Or I see the struggles that maybe he has today, and I hope that I can encourage a little.”

Similarly, participants recounted the critical role their family and friends played in their treatment.

“My wife helps me a lot.”

“Family helps [...] they keep reminding you to do it.”

“All my coworkers... All very supportive. Still watch after me.”

Enabling (Structural) Facilitators—Participants identified program staff as a positive driving force for attending sessions. The words “friendly,” “nice,” “encouraging,” and

“smiling faces” were used to describe them. Participants were unanimous about the role of PR staff as a facilitator of adherence.

“[...] they friendly, they nice.”

Another facilitator was the educational component of sessions. Participants discussed at length the role of learning and reiterating basic information about their disease for completing the sessions.

“I learned how to take my pressure and my oxygen level and learned how to breathe. I didn’t know none of that and been goin’ in and outta the hospital all my life. But they taught me that.”

Proposed Solutions

Participants were asked what is most important in designing a program to help COPD patients complete PR. Insights into several areas was provided, with recommendations addressing predisposing (intrapersonal), reinforcing (interpersonal), and enabling (structural) factors.

Predisposing (Intrapersonal) Solutions—Participants stressed that PR sessions should be kept appealing by including group exercises, goal setting, and continued encouragement from staff. Two types of motivational incentives were suggested: (1) gift items such as food, medical samples, and free PR sessions or time with trainer; and (2) intangible incentives such as acknowledgement of progress or sharing accomplishments with peers and family. They also proposed the use of counseling, both during and after completion of the program.

“Maybe if you had a counselor around to help motivate ‘em cuz you’d be able to tell the ones that not motivated when they first come in the door.”

Second, participants recommended the inclusion of cost-free tobacco cessation services:

“But if they had more smoking cessation programs that insurances will cover.”

Finally, participants proposed expanding the educational component of PR programs because learning about their disease helped them understand their symptoms and make decisions about care:

“We could learn more about what COPD is [...] and it can help you and affect you in your everyday life activities.”

“I think, explain why you take certain medications. [...] I keep doing this every day and I don’t feel any different. You’re gonna save some money so you don’t get this prescription refilled. Then someone says, why aren’t you taking it? [...]”

Reinforcing (Interpersonal) Solutions—Participants expressed a desire to see their entire family included in PR sessions and educated about COPD.

“Sometimes I wish though that they have some requirements for the program where my children who are in their 30s to sit in a session and maybe get a better

understanding cuz I don't sometimes think well they fully understand what I'm going through."

Enabling (Structural) Solutions—Transportation services, flexible scheduling, and financial assistance were the main recommendations for structural solutions. In terms of transportation, suggestions included carpool, door-to-door escort service, and bus vouchers, among others:

"You know, you set your time up for your sessions to be as a group and you just come, you know, carpool together."

"So, it wouldn't be no problem if you maybe had somebody with a van [...] that could go to her house [...] and bring 'em and take 'em there."

"Maybe by some of these transportation buses that pick you up and take you to the doctor and pick you up and take you to your rehab visits. You have a voucher for the bus and something like that."

Participants also stated that PR programs should consider flexible scheduling or offer sessions in multiple locations. Expanded hours of operation and additional locations would also help alleviate transportation difficulties.

"Include scheduling that would accommodate everybody [...] because everybody is on a different time."

"If they schedule them in the evening time, I have no problem getting to them. Morning appointments, I have a problem getting to them."

Participants further recommended financial assistance for patients who cannot afford PR.

"Work on establishing a fund to help people to remain in this program if it wasn't covered by insurance. [...] And if there were some funds available to cover cases where someone's insurance wouldn't cover."

DISCUSSION

Guided by the PRECEDE model, this qualitative study used focus groups with COPD patients to identify barriers and facilitators to completion of PR. Study results showed that health limitations, social support, transportation, financial difficulties, and program features impact the willingness and ability of patients to attend PR. Our data also outline patient-proposed solutions to improve adherence to PR.

PR is a demanding task for COPD patients, who experience shortness of breath, limited mobility, and multiple comorbidities.²⁷ Our results corroborate previous findings that poor functional health is a risk factor for non-adherence.²⁸ They also suggest that personal determination is key for completing sessions. Although resolve has been identified as a predictor of adherence to PR, it has been discussed in the context of readiness as defined by the Transtheoretical Model.²⁹ In our study, participants viewed determination as a personal disposition indicative of empowerment.^{30,31} The commonality of statements such as, *"It's got to be within the individual that's willing to complete that program"* and *"You just have*

to have the will power to wanna do it,” coupled with the lack of references to powerful others, chance, or God, indicates a strong internal locus of control regarding PR.³² Nevertheless, more than half of participants had low adherence, suggesting that internal locus of control may be moderated by other factors, such as self-efficacy.³³

Our data highlight the important role of health education for adherence to PR. Patient education is central to most PR programs and has been associated with improvement in dyspnea³⁴ as well as self-efficacy and self-management skills.³⁵ Our participants, while corroborating previous evidence, felt that education should be provided not only to the patient but also to his/her family to promote understanding of the disease and facilitate emotional and social support. Family involvement is a gold standard for effective treatments and interventions in tobacco cessation,³⁶ substance use,³⁷ and obesity.^{38,39} Harnessing the influence of family members through enhanced understanding of the benefits of PR and a broader understanding of the COPD disease can be a fruitful approach in PR programs.

Living alone or not having a support system, which have been found impactful for participation in PR,²⁹ were identified as major barriers. Conversely, the fellowship of PR peers and staff served as a motivating factor and alleviated the social isolation commonly seen in COPD patients.⁴⁰ Although home-based PR, or telerehabilitation, can reduce barriers related to access,⁴¹⁻⁴³ it may not adequately address social isolation or may even exacerbate it. Future studies of home-based PR need to consider this potentially limiting aspect of tele-rehabilitation. Psychological well-being is an important correlate of quality of life and health outcomes in COPD,^{44,45} therefore it should be part of the long-term evaluation of distance-based programs.

The format and schedule of support groups needs to be carefully considered. For example, the clinical program from which study participants were recruited offers a monthly support group, but attendance is low. On the other hand, educational sessions have assumed some functions of support groups by connecting participants and giving them an opportunity to share experiences while learning about lung disease, respiratory devices, nutrition, or yoga. For the success of support groups, a prior assessment of needs and preferences may be necessary. Finally, in our clinical program, the introduction of a COPD order set for automatic PR referral at hospital discharge has increased the number of referred and enrolled patients, but has decreased adherence to PR, as larger proportion of participants are smokers, have multiple co-morbidities, and diagnosed depression.¹² Referral, while essential for access, needs to go hand-in-hand with programs that address barriers to PR completion.

Along with intra and interpersonal factors, structural barriers such as transportation difficulties and financial burden were discussed. Participants deliberated on the challenges of getting to appointments and the prohibitive out-of-pocket costs that discourage participation. Transportation challenges⁴⁶ and high Medicare copays for PR⁴⁷ have been reported previously. Our results underscore the importance of socioeconomic factors for completion of PR.¹²

The study has several limitations. Although participants were sociodemographically diverse and included all levels of adherence, data may not be applicable to patients in other

programs or geographic areas. As the interviews were retrospective, it may have been difficult for some to recall their experiences. Additionally, we did not interview caregivers or providers. While providers' perspectives in PR have been studied,²⁹ caregivers' perspectives have not been explored, to the best of our knowledge. Hence, caregiver studies may be beneficial, particularly for addressing intra- and interpersonal barriers. The impact of out-of-pocket expenses also remains an understudied factor in uptake and completion of PR.

We previously reported that, relative to high adherence, low adherence is associated with markers of limited functional capacity and current smoking, while moderate adherence is associated with socioeconomic disadvantage.¹² This study expands the understanding of factors that promote or inhibit adherence to PR. Together these 2 investigations highlight the synergistic role of health and socioeconomic status as independent predictors of suboptimal adherence to PR and point to the need for targeted approaches to optimize access to PR for all patients with COPD.

Conclusion

Both health limitations and socioeconomic disadvantage impact the ability of patients to attend PR. Interventions tailored to the needs of patient subgroups should be tested. PR programs should be flexible, accessible, family-centered and should promote patient engagement.

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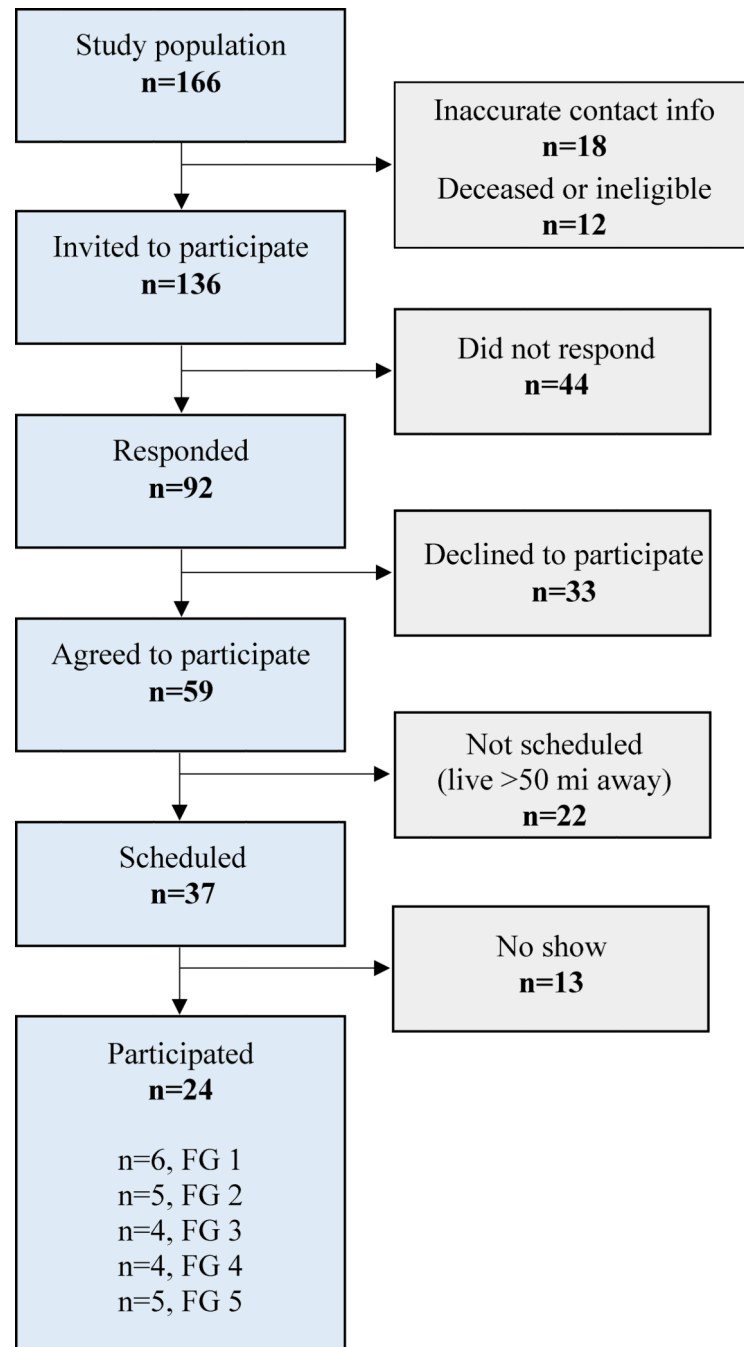


Figure.
STROBE diagram of study sample. Abbreviations: FG, focus group; STROBE, STrengthening the Reporting of OBservational studies in Epidemiology.

Table 1.

Semi-structured Interview Guide

Introductory questions	<ul style="list-style-type: none"> • What do you remember about your pulmonary rehab sessions? • Do you feel that it was hard to complete them all? Why or why not? • Why do you think some people complete all their sessions and others do not?
Overarching question	<i>If we designed a program to help people attend all their rehab sessions, what should it include?</i>
Probe questions	<ul style="list-style-type: none"> • What is your experience with having financial struggles or obligations? Do you think it influenced your ability to attend all sessions? • What do you think about the travel and transportation to the rehab clinic? • Does your family help your pulmonary rehab or does it make it harder? What about living alone? • Do you think your friends or neighbors influenced your ability to attend all your sessions? • What are some things that have helped you attend your rehab sessions? • If a program offered incentives to people to complete all their sessions, what would work for you? What reward or other factor would motivate you to complete all your rehab sessions?
Ending question	<i>What is the most important thing we should know when designing a program to help COPD patients complete their pulmonary rehabilitation?</i>

Abbreviation: COPD, chronic obstructive pulmonary disease.

Table 2.

Sociodemographic and Adherence Characteristics of Participants (n = 24)^a

Characteristics	Total n = 24	FG1 n = 6	FG2 n = 5	FG3 n = 4	FG4 n = 4	FG5 n = 5
Age, yr	62.3 ± 8.6	63.6 ± 11.9	63.0 ± 6.2	64.7 ± 7.2	59.3 ± 12.4	61.0 ± 4.8
Male	54.2	33.3	80.0	50.0	75.0	40.0
Black	66.7	100.0	80.0	50.0	25.0	60.0
High school education	66.7	83.3	60.0	40.0	25.0	60.0
<\$20,000/yr household income	52.4	50.0	66.7	66.7	50.0	40.0
Married or cohabiting	43.4	0.0	25.0	50.0	25.0	60.0
Current smoker	16.7	16.7	0.0	0.0	50.0	20.0
Adherence						
Low (<35% of prescribed sessions)	54.2	50.0	40.0	75.0	50.0	60.0
Moderate (36–85% of prescribed sessions)	20.8	16.7	20.0	25.0	25.0	20.0
High (>85% of prescribed sessions)	25.0	33.3	40.0	0.0	25.0	20.0

Abbreviation: FG, focus group.

^aData reported as mean ± standard deviation or percent.

Table 3.

Unifying Themes, Subthemes, and Representative Codes

Theme	Subtheme	Representative Codes
Barriers	Predisposing (Intrapersonal)	<ul style="list-style-type: none"> • Physical limitations • Lack of motivation
	Reinforcing (Interpersonal)	<ul style="list-style-type: none"> • Lack of social support
	Enabling (Structural)	<ul style="list-style-type: none"> • Transportation difficulties • Financial struggles
Facilitators	Predisposing (Intrapersonal)	<ul style="list-style-type: none"> • Health improvement • Personal determination
	Reinforcing (Interpersonal)	<ul style="list-style-type: none"> • Support from peers • Support from family and friends
	Enabling (Structural)	<ul style="list-style-type: none"> • Flexible scheduling • Program characteristics: helpful staff, educational sessions
Proposed solutions	Predisposing (Intrapersonal)	<ul style="list-style-type: none"> • Incentives to maintain interest • Tobacco cessation support
	Reinforcing (Interpersonal)	<ul style="list-style-type: none"> • Educating the entire family
	Enabling (Structural)	<ul style="list-style-type: none"> • Transportation assistance • Flexible scheduling • Financial assistance