

MESTRADO INTEGRADO EM MEDICINA - TRABALHO FINAL

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Therapeutic adherence and its determinants in 50 to 69 year-old patients: a focus group qualitative research

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Therapeutic adherence and its determinants in 50 to 69 year-old patients: a focus group
qualitative research

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<u>Abstract</u>

Background: Therapeutic adherence is of extreme importance to guarantee a good quality of

life for patients. The factors that influence therapeutic adherence vary from patient to patient

and for personal reasons and include medication-related factors and doctor-patient

relationship.

Purpose: The purpose of this study was to identify the factors that influence therapeutic

compliance, based on patients' perspectives.

Methods: The authors gathered patients to perform a focus group discussion. The focus group

consisted of an interview with open-ended questions to promote the debate between the

participants. Then, the authors analysed, in a qualitative way, the patients' perspectives about

therapeutic adherence.

Results: The main difficulties to therapeutic adherence were daily routine changes, adverse

effects and trust in the healthcare professionals. The main strategies to overcome these

difficulties were help from family and healthcare centres and simplifying the therapeutic

regimen. Also, the participants stated that there should be a better communication between

patients and doctors.

Discussion: The findings in this study were in accordance with the literature. However,

geographic regions and the age gap depicted were narrow, which might not represent the rest

of the Portuguese population.

Conclusion: The information gathered in this study can be used to develop new strategies in

order to make patients more compliant to the therapeutic.

Keywords

Focus group, Portugal, therapeutic adherence

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Resumo

Introdução: A adesão terapêutica é de extrema importância para garantir uma boa qualidade

de vida aos doentes. Os fatores que influenciam a adesão terapêutica variam de doente para

doente, desde razões pessoais a fatores relacionados com a medicação e a própria relação

medico-doente.

Objetivo: O objetivo deste trabalho foi investigar os fatores que infuenciam a adesão

terapêutica, baseado nas opiniões dos doentes.

Métodos: Os autores convidaram doentes de modo a realizar um focus group. O focus group

consistiu numa reunião com questões abertas, de modo a promover o debate entre os

participantes. De seguida, os investigadores analisaram, de modo qualitativo, as perspetivas

dos doentes sobre a adesão terapêutica.

Resultados: As principais barreiras para a adesão terapêutica foram mudanças nas rotinas

da vida diária dos doentes, efeitos adversos da medicação e confiança nos profissionais de

saúde. As principais estratégias para ultrapassar estas dificuldades foram ajuda da família e

dos Centros de Saúde e simplificação do esquema terapêutico. Além disso, os participantes

sugeriram que devia haver uma melhor comunicação entre os médicos e os doentes.

Discussão: Os dados recolhidos neste estudo foram ao encontro do que estava descrito na

literatura. No entanto, a região geográfica e a diferença de idades dos participantes, que é

estreita, podem não representar a restante população portuguesa.

Conclusão: A informação reunida neste estudo pode ser usada para desenvolver novos

métodos que possibilitem uma maior adesão à terapêutica.

Palavras-chave:

Focus group, Portugal, adesão terapêutica

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Introduction

Therapeutic adherence is influenced by various factors, namely patients' socioeconomic conditions, their trust in the professional healthcare workers, treatment efficiency and personal factors. The patient must not have a passive attitude regarding their treatment. Instead, there must be a cooperation between doctors and patients, especially in the process of decision-making, where patients should be well-informed by their doctors¹. It is widely known that a good therapeutic adherence guarantees a better quality of life and reduces the impact that patients' pathologies have on their lives².

Healthcare physicians should be concerned about their non-compliant patients because non-adherence to therapeutic has a negative impact on their lives, such as worsening of health status, more doctor's appointments, increase in hospitalizations and urgent care. Furthermore, because of this non-adherence, these patients will be uncapable of performing as well as before in their jobs, lowering their productivity and, in the worst scenario, non-compliance can lead to death^{1, 2}.

In Portugal, there is a lack of studies regarding the patients' point of view about therapeutic adherence, which makes their compliance unpredictable for medical doctors. Thus, the main point of this paper is to determine which factors make patients adhere to medical treatment or not¹.

Therapeutic adherence is not only about taking the prescribed medicine, but also lifestyle changes, such as having a healthy diet and physical exercise and not missing doctor's appointments. According to patients, this point about lifestyle changes can be assured by the Healthcare Centres, by motivating the patient to do them, warning them about the consequences of non-compliance and morbidities as a result of bad disease monitoring³.

Due to the fact that there are few studies about this theme taking into consideration patients' perspectives, hearing their opinions is essential before starting a therapeutic regimen in order to make the treatment effective. Hence, by performing a qualitative research, we can gather in-depth information from the participants about this fundamental theme that has a crucial impact in their lives and, since the information is scarce, we believe this is the best approach³.

Therefore, this study used a focus group. A focus group is a method of qualitative research in which people are interviewed about their beliefs concerning a certain subject. The moderators start by asking the participants open-ended questions to promote the debate. Moreover, the

participants are encouraged to discuss between them their different points of view instead of talking alone to the interviewers, so that they do not feel inhibited to express their opinions. It is also important to inform them that there are no right or wrong answers because the aim of a focus group is to explore every possible opinion and perspective⁴.

All things considered, the aim of this study was to identify, in a qualitative way, the barriers to therapeutic compliance and strategies to overcome these difficulties that lead patients to adhere to treatment to have a better quality of life.

Material and methods

Study design

Focus group qualitative research.

Selection of participants

Portuguese people aged 50 to 69 years-old, registered in a Family Health Unit of the Group of Health Centres Pinhal Litoral, Regional Health Administration of the Centre of Portugal (ACeS (Agrupamento de Centros de Saúde) Pinhal Litoral, ARS (Administração Regional de Saúde do Centro). A population sample, as diverse as possible (employed, retired, low literacy, high literacy and city and rural environment) was obtained. A total of 7 patients were selected. No financial benefits were given to the participants.

Data collection

Data collection was performed during a focus group discussion, after the participants' consent was obtained. The study used a qualitative analysis of an interview with open-ended questions, previously elaborated by the moderators, so that the most important points would be asked, such as trust in healthcare professionals, drugs' adverse effects, family support and how primary healthcare centres can help patients increase therapeutic compliance. The participants consented to the audio recording and processing of their data and opinions collected during the focus group. Furthermore, they were informed that they could withdraw from the study at any time. The language used during the focus group was Portuguese. This study was approved by the Ethics Comission of Regional Health Administration of the Centre of Portugal. (Appendix I)

Data analysis

The qualitative analysis of the data collected in the focus group was executed manually by the investigators, directly transcribing the audio recordings. Consequently, the determinants of therapeutic compliance expressed by the participants were identified, so that their opinions could be systematized.

Results

Barriers

The participants stated that sometimes they do not comply with the prescription correctly because they forget, especially when it is not taken daily or if there are changes in their daily routine, such as not having dinner at the same time or when they have guests at their house. Moreover, some patients said they stopped the medication due to the price or because they were influenced by other people's opinions. On the one hand, some participants stated that they stopped taking the medicine because they felt better. On the other hand, some of them stopped it because they didn't wait for the medicine to take effect. Regarding the adverse effects, they pointed out that if the adverse effects are worse than the symptoms that brought them do the doctor, they do not finish the therapeutic. Another important factor to take into consideration is the trust patients have in their doctors. (Table 1)

Table 1: Determinants that make therapeutic adherence difficult

Topics	Quotes
Forgetfulness	"Medicines that are not taken daily
	contribute to forgetfulness";
	"Sometimes I forget to take my medicine,
	because it is only to be taken every 3
	days"
Trust in the doctor	"The doctor must "waste time" explaining
	the medication to their patients";
	"Medication that fits patients' daily life"
Daily routine changes	"The dinner is never at the same time";
	"When I have company for dinner, I get
	distracted by the conversation and forget
	to take the medication";
	"As I spend months working abroad,
	sometimes the medication runs out and I
	only take it again when I return to
	Portugal"
Adverse effects	"The package leaflet scares me";
	"If the side effects are worse than the
	symptoms I have, I stop taking the
	medicine"
Price	"I have already stopped taking the
	medication because it cost 60€ and only
	lasted 28 days"
Other people's opinions	"Once, I stopped taking the medicine
	because a friend of mine told me that it
	made things even worse"
Disease symptoms	"I did not finish the therapeutic regimen
	because I got better";
	"Since some medicines take a few days to
	take effect, I have stopped taking them"

Enablers

The participants stated that the strategies they use in order to fulfill the therapy are the following: having notes in the kitchen to write if they have taken the medicine or not; having the pillbox in a place they know they will be (for instance, medication to be taken in the morning will be placed in the bedroom). The patients suggested other ways to facilitate therapeutic adherence such as taking the medication at the same time and reducing the medication intake by using "2 in 1" pills. Another extremely important factor to comply with therapy is the perceived seriousness of the disease, which means that if the patients think that if they stop the treatment, they will die, then they make sure they will not forget to take the medicine. (Table 2)

Table 2: Determinants that facilitate the therapeutic adherence

Topics	Quotes
Reminder	"I have a note on the fridge, so that I do
	not forget to take the medicines"
Simplifying the medication regimen	"Taking the medication at the same time
	helps a lot";
	"Taking medication "2 in 1" (eg. for
	dyslipidemia and high blood pressure in
	the same pill)
Disease severity	"The doctor said it was for the rest of my
	life";
	"The doctor told me that if I did not take
	the medicine, I would die"
Medicine box location	"As I take the medicine in the morning, I
	have the pillbox in my bedroom () so, I
	take it as soon as I wake up"

Side effects

The side effects of the medication are a major factor affecting therapeutic adherence. In order to avoid the discontinuance of treatment because of the side effects, the participants considered that doctors should take time to explain the mechanism behind the therapeutic and the possible side effects. In addition to this, the interviewees reported that the doctors should individualize treatment because every patient is different and reacts differently to medication. On the one hand, some patients claimed that even though they experienced side effects, they did not stop the treatment. On the other hand, patients who were being treated for depression could not manage the side effects and, consequently, did not wait the time required for the medicine to take effect, ending the therapeutic voluntarily. (Table 3)

Table 3: The importance of the side effects

Topics	Quotes
Communication with the doctor	"Doctors must explain better the medicine
	effect and the possible side effects";
	"It never happened to me that the doctor
	did not have time to explain to me the
	adverse effects";
	"It is important to individualize the
	treatment";
	"If the doctor is prescribing a certain
	medicine, it is because he/she has
	reasons to do so"
Adverse effects	"I have never stopped taking the
	medication because of the adverse
	effects"
Sensibilization	"People have mild symptoms and do not
	have the patience to wait for the medicine
	to take effect";
	"Antidepressants take about three weeks
	to take effect, but in the first few days
	most patients experience loss of appetite,
	nausea and diarrhea. Some of these
	patients feel so much these effects that
	they cannot wait for three weeks"

The role of the family

Family plays an essential role concerning therapeutic adherence. Some participants reported that they have to remind their relatives to take the medication. However, others considered that being constantly asked if they have taken the medication becomes excessive and leads to unnecessary overpressure and, as a result, they feel they will not heal from their disease. Also, the participants mentioned that the pill dispensers are helpful for elders to avoid forgetting to take the medication. (Table 4)

Table 4: Family role

Topics	Quotes
Reminder	"I always have to remind my son to take
	the medication";
	"For older people, there are those pill
	dispensers";
	"I have to keep reminding my husband
	because he is very careless"
Pressure	"It annoys me that people are constantly
	asking me if I have taken the medication
	or if I feel fine";
	"When we are constantly asked if we are
	fine, it seems that instead of getting
	better, it seems that we get worse than
	before";
	"It annoys me that my husband asks me
	every day if I feel better"

The importance of Primary Healthcare Centres

The main role of Primary Healthcare Centres is to provide care to patients, improving their quality of life. In order to achieve this, the participants suggested the promotion of lifestyle changes to avoid being treated pharmacologically, such as in cases of diabetes and dyslipidemia. Another activity suggested by the patients was clarifying some medical myths that patients have about their diseases. Furthermore, it was stated that prescriptions for chronic diseases should be for as long as possible, so that patients will not need to come in every month just to renew their prescriptions. (Table 5)

Table 5: The importance of Primary Healthcare Centres

Topics	Quotes
Accessibility	"Having the doctor's mobile phone
	number would help answer specific
	questions, or by email";
	"Sometimes the appointments are so
	short";
	"Doctors do not explain everything
	because they do not have time"
Lifestyle changes	"In the case of dyslipidemia, before
	starting the medication, I had to change
	my lifestyle"
Prescription renewals	"Long-term (3-6 months) prescriptions for
	chronic diseases, thus avoiding coming
	so often to the Health Center to renew the
	prescription"
Treatment individualization	"Patients' age plays a key role";
	"Demystifying the "ghosts" that people
	create in their heads";
	"Health centres should promote lifestyle
	changes, so that patients do not think so
	much about their illness and,
	consequently, have a better quality of life"

Discussion

This study assessed, in a qualitative manner, the determinants that influence therapeutic adherence and how difficulties can be overcome in order to increase patients' adherence to therapeutic. There aren't many studies in Portugal about this topic and, in most cases, doctors' perspectives are used rather than patients' points of view.

As previously mentioned, there are many factors that can jeopardize therapeutic adherence and, to make patients more compliant, there are several strategies that work better when combined, rather than following one alone⁵.

Firstly, regarding the side effects, most of the patients considered them as one of the reasons for non-compliance to therapy, due to lack of trust in doctors, scepticism about the medication's efficacy and new symptoms worse than those they had in the beginning. This means that if health practitioners warned their patients about possible adverse effects, they would not be so sceptical about the medication and, therefore, they would not cease the treatment⁶. Although some patients claimed that they did not quit the treatment because of the side effects, for others it was a major barrier to overcome, as some medicines take weeks to take effect, they could not cope with the side effects while not seeing any signs of improvement of their health status⁷.

Secondly, Primary Healthcare Centres have a significant impact on patients' lives. The lack of accessibility to healthcare providers decreases therapeutic adherence, so if physicians had more time to explain the therapeutic, a better doctor-patient relationship would be formed and, consequently, therapeutic adherence would increase⁸. Additionally, the respondents reported that while doctors have the knowledge about patients' health condition, there should not be a paternalistic relationship. Instead, the participants insisted on having an active role in the definition of therapeutic, but in order to achieve that, they should be properly informed by their doctors^{5, 9}.

Thirdly, according to the participants, the main barrier to therapeutic adherence was the doctor-patient relationship, especially the quality of the communication and the presence or absence of trust. They reckon that sometimes appointments are performed at such a frantic pace that doctors do not have time to talk to the patient and explain the treatment. However, in order to enhance the doctor-patient relationship, the doctor must give clear explanations, ask the patient about his concerns and reach a consensus regarding the therapeutic. In addition to this, the respondents related that health physicians should individualize the therapeutic and

not treat every patient the same way. In other words, each patient is unique and should be treated according to their own characteristics, especially age, socioeconomical status, level of education and patient satisfaction¹⁰⁻¹².

Furthermore, this study is in accordance with other studies concerning the frequency of prescribed medication^{13, 14}. In other words, therapeutic compliance increases when the prescribed dosing is to be taken once daily and all medicines are taken at the same time. Also, it was found that patients with poor health status are more willing to adhere to the treatment, while others with mild symptoms may not be entirely compliant¹⁵. Nonetheless, the evidence regarding disease severity is not consistent enough to confirm that patients with less severe disease would not comply as easily as patients with greater disease severity¹⁶.

Lastly, family plays a crucial role concerning therapeutic adherence, as family members provide support and help patients by reminding them to take the medication. It has been proven that having family support makes the patients more motivated and more likely to comply with the treatment¹⁷. Nevertheless, the respondents reported that family can be considered as a barrier too, due to the fact that excessive care leads to unneeded pressure, which might make them feel that their health status is deteriorating instead of improving.

All in all, the strategies suggested by the patients to overcome the previously mentioned difficulties are the following: using of reminders, pill dispensers for the elderly, family support, asking for feedback to the patient, adjusting the medication to fit the patients' daily life, motivating the patient to be adherent and informing about the possible adverse effects. Moreover, the interviews added another important strategy in order to make them more compliant: simplifying the therapeutic regimen, either by reducing the number of intakes per day or taking the medication at the same time¹⁸. Also, they added that doctors could prescribe medication for longer periods, so that intervals between appointments are longer and, as a result, they do not have to come every month just to renew the prescription¹⁹.

However, this study has some limitations, such as demography (the participants lived in the same city), which may not represent the whole country, even though some of them lived either in urban or rural zones. Also, the age gap was narrow (50 to 69 years old), so for future focus groups it would be advisable to include younger and older patients because age might influence therapeutic adherence.

Conclusion

In sum, this study was able to identify barriers related to therapeutic adherence based on patients' opinions, namely daily routine changes, forgetfulness, doctor/patient relationship, health status and strategies to overcome these factors, such as support from family and healthcare centres, notes/reminders and simplifying the treatment regimen. Therefore, the data collected will guide physicians in finding new approaches to make patients more compliant to the treatment.

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COMISSÃO DE ÉTICA PARA A SAÚDE

PARECER FINAL FAVORÁVEL		PArter Faronal Leterilo. 23.09.6021
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Assunto:	através de focus group." (processo 76-2021). Autores: Fernando Manuel Cardoso Matos; J Velho Faculdade de Medicina da Universidade de Coi	tes em indivíduos dos 50 aos 69 años: estudo qualitativo osé Augusto Rodrigues Simões; Denis Alexandra Cunha mbra/Administração Regional de Saúde do Centro / al/Unidade de Saúde Familiar Santago de Leiria

Os autores do estudo pretendem avaliar, de forma qualitativa, os determinantes que levam aos doentes aderirem ao tratamento e, deste modo, aumentar a sua adesão terapêutica, com o interpreta de melhorar a sua qualidade de vida.

Tendo em conta os objectivos propostos, os autores pretendem realizar um Focus Group nas várias Unidades Funcionais do ACeS Pinhal Litoral.

Os participantes são convidados a participar no estudo e a expor as suas crenças sobre determinado tema, através de perguntas feitas pelos entrevistadores, de forma a discutir diversos pontos de vista. Será formado um grupo de 5 a 8 pessoas com idades entre os 50 e 69 anos)

A duração da reunião será, no máximo, 2 horas e audiogravadas com o devido consentimento de todos os participantes.

Os autores não fazem referência ao tipo de análise qualitativa que irão realizar, nem apresentam o respectivo guião da reunião.

Estão garantidas todos os aspecto ético legais.

Solicita-se posteriormente o envio do relatório final do estudo.

Pelo exposto somos de parecer Favorável à realização do estudo

O Relator e Presidente da CES-ARS do Centro

Prof^a. Doutora Isabel Vitória Figueiredo

Appendix II - Focus group' script

Parte I:

Apresentação dos moderadores

Explicação da realização deste focus group

Parte II:

Perguntas

- -Sentem efeitos secundários ou indesejados quando tomam a medicação?
- -Como acham que esses efeitos podem ser melhorados?
- -Têm dificuldade em cumprir a prescrição feita pelo médico?
- -Esquecem-se de tomar a medicação?
- -Que fatores consideram que levam a este esquecimento?
- -Do vosso ponto de vista, há algo que pudesse aumentar a adesão terapêutica?
- -Consideram que a vossa família poderia ajudar-vos a cumprir a medicação?
- -Consideram o fator económico a que não tomem a medicação?
- -Alguma vez deixaram de tomar a medicação por se terem sentido melhor/pior?
- -Na vossa opinião, os centros de saúde ou farmácias poderiam fazer algo para que aumentasse a adesão terapêutica?

Parte III

Agradecimento e lanche final

Appendix III - informed consent

CONSENTIMENTO INFORMADO, LIVRE E ESCLARECIDO PARA PARTICIPAÇÃO EM INVESTIGAÇÃO

Por favor, leia com atenção a seguinte informação. Se achar que algo está incorrecto ou que não está claro, não hesite em solicitar mais informações. Se concorda com a proposta que lhe foi feita, queira assinar este documento.

<u>Título do estudo</u>: Adesão terapêutica e seus determinantes em indivíduos dos 50 aos 69 anos: estudo qualitativo através de focus group

Enquadramento: Estudo para Trabalho Final de Mestrado Integrado em Medicina da Faculdade de Medicina da Universidade de Coimbra, sob a orientação do Professor Dr. José Augusto Simões e da Dra Denise Velho

Explicação do estudo: O objetivo da realização deste estudo é identificar os fatores que levam aos doentes aderirem à terapêutica, com o intuito de melhorar a sua qualidade de vida. Sendo assim, o estudo será feito através de focus group, com um grupo de 5 a 8 pessoas (dos 50 aos 69 anos), as quais serão convidadas a expressarem as suas opiniões sobre a adesão terapêutica. A duração da reunião será, no máximo, 2 horas e audiogravadas. A reunião terá 2 moderadores que irão facilitar a discussão, colocando diversas questões aos participantes. As gravações serão posteriormente destruídas.

Condições e financiamento: Não há pagamento aos colaboradores nem aos participantes. Não há proveitos financeiros deste projeto. O estudo é financiado pelos próprios autores. A participação neste estudo é de caráter voluntário e não há prejuízos se os participantes não desejarem participar ou desistirem. Este estudo foi submetido à Comissão de Ética da Administração Regional de Saúde do Centro.

Confidencialidade e anonimato: As respostas obtidas da gravação da reunião serão de acesso exclusivo dos autores do estudo. A gravação será posteriormente eliminada. Não haverá registo de identificação, garantindo, assim, o absoluto anonimato dos participantes. Todos os dados recolhidos da gravação da reunião serão apresentados no âmbito do Trabalho Final do aluno e discutidos entre pessoas com formação médica.

Investigador: Ferna de Coimbra	ando Matos, aluno do 5º ano de Medicina da Faculdade de Medicina da Universidade
Assinatura/s:	
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fornecidas pela/s pe recusar participar n estudo e permito a u	compreendido este documento, bem como as informações verbais que me foran essoa/s que acima assina/m. Foi-me garantida a possibilidade de, em qualquer altura este estudo sem qualquer tipo de consequências. Desta forma, aceito participar nesto utilização dos dados que de forma voluntária forneço, confiando em que apenas serão tinvestigação e nas garantias de confidencialidade e anonimato que me são dada: /a.
Assinatura:	

	SE NÃO FOR O PRÓPRIO A ASSINAR POR IDADE OU INCAPACIDADE
	(se o menor tiver discernimento deve <u>também</u> assinar em cima, se consentir)
NOME:	
BI/CD Nº:	DATA OU VALIDADE/
	ENTESCO OU TIPO DE REPRESENTAÇÃO:
ASSINATU	JRAU

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Consentimento Informado, Livre e Esclarecido para:

Estudo e focus group audiogravado no contexto da Tese de Mestrado "Adesão terapêutica e seus determinantes em indivíduos dos 50 aos 60 anos: estudo qualitativo através de focus group"

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