

# Unmet expectations of medications and care providers among patients with heart failure assessed to be poorly adherent: results from the Chronic Heart Failure Intervention to Improve Medication Adherence (CHIME) study

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## Abstract

**Background:** Ineffective medication management contributes to repeated hospitalisation and death among patients with heart failure. The meaning ascribed to medications and the influence of meaning on how patients manage medications is unknown. The purpose of this study was to explore the meaning and expectations associated with medication use in high-risk, non-adherent patients with heart failure.

**Methods and results:** Patients ( $n=265$ ) with heart failure were screened for adherence to prescribed medication using the Morisky medication adherence scale (MMAS). Patients (MMAS score  $<6$ ;  $n=44$ ) participated in semistructured interviews, analysed using qualitative content analysis. Of 17 initial themes (223 representative segments), the overarching theme ‘unmet expectations’ consisted of two subthemes ‘working to be heard’ by professionals and ‘resignation’ to both the illness and medications. Patients’ expectations were challenged by unexpected work to communicate with providers in general (72 representative segments), and specifically regarding medications (118 representative segments) and feelings of resignation regarding the medication regimen (33 representative segments).

**Conclusions:** These findings suggest that unmet expectations contribute to poor medication management. Improved listening and communication by providers, to establish a common understanding and plan for managing medications may strengthen patient beliefs, resolve feelings of resignation and improve patients’ ability to manage medications effectively.

## Keywords

Adherence, patient-provider communication, patient-reported, qualitative research, self-management, person-centered medication management

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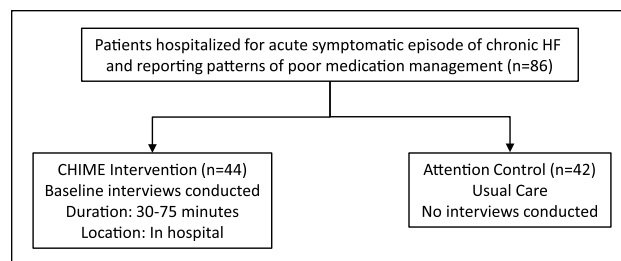
## Introduction

The American College of Cardiology, American Heart Association and European Society of Cardiology guidelines recommend medications to reduce morbidity and mortality in heart failure.<sup>1,2</sup> However, approximately 50% of patients with chronic heart failure do not consistently take medications according to the dosages and frequencies tested in the clinical trials designed to establish their effectiveness.<sup>3–5</sup> The language used to describe this malady is often divided by the suspected aetiology. The term concordance is used to denote that the lapse is due to ineffective communication or lack of agreement between patients and physicians with regard to the regimen.<sup>6,7</sup> Erstwhile, adherence refers to the process of following a set of directions, i.e. the prescription, and assumes that agreement for how, when and what to take has been reached. The World Health Organization<sup>8</sup> and the most recent international caucus on taxonomy for medication use have determined that adherence to medications refers to the processes by which a person takes medication as prescribed, and is further divided into three quantifiable phases, initiation, implementation and discontinuation.<sup>9</sup> A final term, persistence, refers to sustained filling and refilling of a prescribed medication over time, an indication of commitment to a medication regimen that is a particularly useful term in chronic illness management such as heart failure.<sup>9</sup> Linguistics aside, nearly four million hospitalisations and over 300,000 deaths occur in the USA each year, with similar rates in Europe, due to medication use that is inconsistent with the specified dosages and frequencies shown to be effective for improving morbidity and mortality in heart failure.<sup>10,11</sup>

Many factors have been associated with poor medication management, apart from incongruent communication.<sup>12,13</sup> In patients with heart failure, the most commonly reported reasons for medication non-adherence include forgetting, fatigue and symptom persistence.<sup>14–16</sup> The nature and frequency of heart failure symptoms pose additional barriers to adherence,<sup>17–20</sup> which, due to individual-level variations make generalised solutions and recommendations difficult.

The most common expectation that patients with heart failure have of their medicines is symptom relief.<sup>21</sup> Not surprisingly, symptom persistence is a primary reason for early discontinuation of medications in clinical practice and for withdrawal from participation in clinical trials.<sup>4,22</sup> Lack of improvement in symptoms such as fatigue and orthopnea have been found to lead patients to lose confidence and discontinue study medicines.<sup>14</sup> The most common symptom in heart failure, fatigue,<sup>16,23</sup> is strongly related to discontinuation of medication taking.<sup>14,15,17,24,25</sup>

Although many studies have explored reasons for discontinuation and poor adherence among patients with heart failure, few have used interviews specifically among patients assessed to be non-adherent to illuminate the experience of managing medications and to explore the meaning



**Figure 1.** Flowchart of study enrollment for qualitative interviews within the CHIME trial.<sup>36</sup>

and expectations that patients ascribe to medications.<sup>23</sup> The meaning–response theory helps to frame the way people view medications and medication management in chronic illness.<sup>26</sup> Constructs in this theory include intention, expectation, understanding, cultural values, feeling cared for, and caring for self.<sup>27–29</sup> The meaning associated with medications, expectations, understanding of the purpose of medications, cultural values, and perceptions of care can influence adherence either negatively or positively. The aim of this study was to describe patient expectations related to medication use in heart failure, and to explore the relationship between expectations and adherence.

## Methods

### Participants and setting

This study represents baseline interviews from a larger randomised trial, the sample and setting of which have previously been described.<sup>36</sup> Of those participating in the intervention ( $n=44$ ), baseline interviews were conducted in the hospital (Figure 1) during a time period of one year (August 2008 to September 2009). However, to summarise the current study, patients ( $n=265$ ) who were admitted to a large university-based hospital for acute, decompensated heart failure were asked to participate, and were screened for risk of poor medication adherence using the Morisky medication adherence scale (MMAS). Of these, 62% ( $n=165$ ) received an MMAS eight-item score of 6 or greater and were ineligible for participation; 86 patients were enrolled and randomly assigned to a new intervention to support medication management ( $n=44$ ) or attention control ( $n=42$ ). Patients' interviews were guided by the meaning–response theory to evaluate the expectations of medications. The institutional review board approved the study, and all participants completed informed consent prior to enrollment.

### Data collection

This qualitative descriptive study consisted of semistructured interviews guided by the meaning–response theory, which we used to identify areas for in-depth exploration

with the participants in the study.<sup>28,29</sup> We used the major constructs of the theory (intention, expectation, understanding, personal values, feeling cared for, and caring for self), to guide the interview. The interviews began with an open-ended question: ‘Tell me about your experiences of taking medicines?’ Additional probes followed the opening question. The sequence of patient questions was structured as follows, but could be posed in a different order, because the intention of the interview was to let the interviewee freely narrate about experiences of medication taking: ‘What is your understanding of how long you will take your medication?’ ‘What is your understanding of the helpfulness of the medications?’ ‘What are your expectations for what the medicines will do for you?’ ‘How do your medicines affect your activities of daily living?’

The interviews were performed during hospitalisation and took place at a convenient time identified by the participant, and lasted approximately 30–75 minutes. All interviews were audio-taped and transcribed, and field notes were used to contribute selected additional data, such as patient body language and aspects of non-verbal communication.

### Data analysis

The interviews were analysed using content analysis methods.<sup>30–32</sup> The text from the interviews was first read several times to become familiar with the data and to form an impression of the material as a whole. Subsequently, meaning units, that is, either a phrase or a full sentence, were independently coded and categorised by two researchers (IE and BBG) trained in qualitative methods. Disagreements in coding were rare, and – when they did occur – they were discussed until consensus was reached. The meaning units were then read and compared with each other. In the next step meaning units describing qualitatively similar conceptions were grouped together. This grouping resulted in a limited number of themes. The content analysis was performed in accordance with the tradition of hermeneutics by reading, re-reading, and checking texts; analysis continued until no further information could be retrieved from the texts.<sup>32</sup> Responses were categorised by content, not in relation to the posed questions or chronologically.

Methodological rigour was maintained by the use of audit trails, memos and peer debriefing with experts in heart failure, medication adherence and the theory guiding the study. Member validation, a technique to underpin the validity of qualitative data,<sup>33</sup> was conducted by informally engaging the participants to clarify the meaning and intention of their experiences after audiotapes were reviewed. This exercise serves to keep interpretations of the patient experience true to the source. The researchers’ own pre-understanding is found within the field of clinical cardiology, nursing, psychology and anthropology, and the team was composed of researchers from the USA and Sweden.

While the pre-understanding is an integral part in any qualitative research method, the team’s composition represented diverse nationality as well as professional backgrounds, which broadened the competence.

### Results

Of the 44 participants interviewed, the average age of the participants was 60 years ( $\pm 11.6$ ), and most were African-American ( $n=32$ ; 73%), men ( $n=23$ ; 52%), not married ( $n=25$ ; 57%), and had completed less than 12 years of education ( $n=31$ ; 72%) (Table 1).

Of 17 initial themes (223 representative segments), the overarching theme, ‘unmet expectations’, consisted of two subthemes ‘working to be heard’ by professionals and ‘resignation’ to both the illness and medications. The subthemes are both describing the frustration of unmet expectations and therefore together form the overall theme. A more detailed description of the themes will follow below.

### Themes

Findings from the analysis represented an overarching theme, unmet expectations, composed of two subthemes, ‘working to be heard’ by healthcare professionals, and ‘resignation’ to the medications and the illness. The subthemes represent the meaning units most commonly and independently represented in the coded segments. Unmet expectations was a broad characterisation of medications, and was reported as a contextual difficulty that contributed to the complexity of everyday life. A chronic condition such as heart failure requires taking many different medicines at several different times a day, organising pills, appointments and often meals to coincide with pills, and structuring time in the day for medication taking. The complexity and work associated with medication taking is well described.<sup>34–36</sup> In the present study, informants particularly emphasised the need to plan ahead for when to take different pills, such as diuretics. Informants described how medications created limitations in planning daily activities because they chose to stay at home or had to plan to wear diapers to be safe. An additional aspect that required planning and made regularly taking medicines difficult for some were the costs: ‘I just explain to him that, say “look doc, I don’t live in your neighborhood you got to come down to my level”.’

For a majority of patients in this cohort the work involved in managing medications was unrewarded by a compensatory change. Amelioration of symptoms was not always associated with adherence, resulting in consternation with the tasks involved and devaluation of medication management. Expectations were not met. For example, ‘If it helps, I’ll take it, if it don’t, we’ll get rid of it and get another one.’ Another stated the sentiments of many, ‘I expect the symptoms to be decreased and I expect the

**Table 1.** Demographics of the sample.

Characteristic	Patients (n=44)
Age, years	
Mean ( $\pm$ SD)	60.24 (11.60)
Median (IQR)	62.09 (17.79)
Sex	
Male	23
Female	21
Race	
White	12
Non-white	32
Level of education	
0–12 years	31
$\geq$ 13 years	13
Diabetes	25 (58.14)
Hypertension	37 (86.05)
Lives alone	
Yes	12
No	32
Marital status	
Married	19
Not married	25
ACE-I prescribed	21
Beta-blocker prescribed	38
Diuretic prescribed	39
Aldosterone antagonist	17

ACE-I: angiotensin-converting enzyme inhibitor.

medicines to help maintain that decrease and when they stop doing that, I expect it's time for somebody to change the medicine or take me off of it.' However, when a perceived change was needed, patient voices could not be heard.

Sub-theme 1, 'working to be heard', was exemplified by reports of the difficulty patients experienced communicating with health professionals regarding various aspects of the medication regimen ( $n=72$  general segments and 118 specific to medication management). For example: 'Many times I have to ask to get the type of information that I ultimately need in terms of the ah, length of use, that kind of thing. It's sometimes too much effort I have to put in to get the answers out of the doctors, but I'm willing to do that, obviously.' The information they received from professionals was reported as too sparse, not directly focused on the patients' primary concerns, and consisting of too little reciprocal dialogue.

Because of the undue effort expended to attain good communication with health professionals, informants sometimes found other ways to get the information they needed to fix their medicine-taking, for example: 'After the doctors give me information then I go to the internet and check it out.'

In contrast to the majority of interviews, a few informants described 'good care', their perception of which stood

in stark contrast and bore witness to the value patients attribute to listening and to discussing medication-taking behaviours as fluid not static, as opportunities for second chances not retribution. These patients gave examples of how professionals took the time to listen carefully to them: 'Well, Dr. (NAME) is very supportive. He's not walking out when he's walking in. He's made it very clear to me that even when I'm not, I guess when I'm not compliant, that he's not going to fire me. The nurses are always very nice, if I could get (NAME) to shut up and let me get a word in edgewise. She's a talker.' When communication with professionals worked well, it was characterised by a respectful approach from both parties: 'They act like you're more than just numbers, you know. Yeah, they talk to me like I'm on their level, you know and it's kind of fun in a way, you know, they make it like that.'

In sub-theme 2, 'resignation', the majority of responses were from a perspective of resignation, both to the medication regimen and to the illness itself ( $n=33$  representative segments). For example, 'Yeah, they prescribe them and I take them and that's all I know.' In another case, the resignation was evident when a patient said, 'The doctor just tells me that it's a medicine I need and I have to take his word for it.' Another indication was the statement by a number of patients regarding the conscious decision to do it. Some reported acceptance of taking the medicines as a simple, straightforward decision. For example, 'I feel it's just a normal condition of living.' And another reported, 'You get used to anything that you do consistently; It's a way of life that I have become accustomed to.'

However, the scope of the theme was not limited merely to acceptance. Rather, the responses reflected a strong association between commitment to taking the medicines and the intention to stay alive. As one person stated, 'If I don't take the medicine, I don't live; so, I take the medicine.' While some were heavy-hearted and resigned, others saw the burden as light, given the weight of the life in exchange. For example one patient responded, 'I'm very happy that I'm able to take the medicines that I have because if I don't take the medicine, I won't be able to live.'

On a much broader scale, resignation to taking the medicines was acceptable and held value and meaning because it was recognised as a requirement for managing symptoms. For example, the pills were acceptable because they were associated with an expectation of results – the relief or amelioration of symptoms. The participants expressed, 'If I'm takin' medication for shortness of breath, if I'm takin' it to help me, it will cause my breath to breathe better, I can walk better, you know, do things a whole lot better than I'm doing it now.'

The two sub-themes together formed the basis of the overarching interpretation of the main theme, 'unmet expectations', which was about patients' hopes for relief from medications and help from providers to manage medications that instead proved to be unmet expectations.

Relief of symptoms and side-effects and unexpected consequences of the medicines, as well as unexpected work to manage the medicines or to communicate with providers about the effects (or perceived lack of effect) of the medicines wove a common thread throughout the interviews.

The informants described experiences of unexpected side-effects from medicines in many ways, including perceived changes in sensory perceptions, sexual function and malaise. An example of the ambiguous nature of this experience is: 'But most of the medicine I take seems to take all my taste buds away, you know, so it's very hard to take. I started like getting jerky feeling and stuff.' The side-effects were reported to be quite bothersome, and even if the intention was to take the medicines, the unexpected consequences sometimes made it hard. An example of this is: 'You don't know what you're gonna take, you don't know what they're gonna give you, you don't know the reaction you're gonna get. I said if I take it twice and it don't do nothing; I'm carrying it back. It ain't no good for me.' The expectation from the informants was that the medicines would reduce symptoms and make life easier, not create trouble, as exemplified in this quote: 'Sometimes, they do [create trouble] cause I run to the bathroom every minute or two.'

## Discussion

Of 17 initial themes (223 representative segments), the overarching theme, 'unmet expectations', consisted of two subthemes 'working to be heard' by professionals and 'resignation' to both the illness and medications. The main theme, 'unmet expectations', helps to explain poor adherence among this cohort of predominantly African-American patients with heart failure. Although providers, perhaps subconsciously, approach patients about medication-taking from a perspective that is driven by guidelines for medication use and assumes 'adherence' to prescribed, evidence-based medications to be the goal, patients in this study reported different experiences. Patients had expectations for care that were associated with a far more dynamic, communicative, ongoing dialogue about the medications, and viewed medication management as only one aspect of living with heart failure. Examples of patients' desires for ongoing discussion with providers about how to manage medicines, for instance when symptoms persist, or when medication side-effects became a dominating issue in daily life, were many. And yet, patients in this study found communication with providers to be hard work. Ultimately, they reported the experience of managing medicines 'alone', in isolation from care-givers and the provider team. This disconnect was interpreted by providers as 'non-adherence', yet, is it that simple? Expectations for both patients (they feel they fail) and providers (the presumed plan of care is not executed) were 'unmet'.

Patients in this study were initially assessed to be 'non-adherent' using the Morisky patient reported outcome

survey.<sup>34,35</sup> In subsequent in-depth interviews to explore the meaning and expectations held, patients overwhelmingly characterised the experience of medication-taking as being fraught with unmet expectations. These unmet expectations contribute in significant and avoidable ways to poor adherence in patients with heart failure. The reports of the experience of medication-taking support existing literature describing the work of medication-taking.<sup>36,39</sup> However, in the present study, interviews uniquely represent patient expectations of providers, the health system, and the medications themselves that are not met. These 'unmet' expectations depict an avoidable and disappointing gap in the life experience of managing medications for chronic illness.

### Working to be heard

Two subthemes of unmet expectations were further specified in these findings, the first of which was working to be heard by professionals. This finding supports existing research related to shared decision-making,<sup>40</sup> goal-setting<sup>41</sup> and partnerships,<sup>42</sup> and suggests opportunities for providers to improve listening and effectively close this reported gap.

Expectations for shared decision-making and shared goal-setting were represented by a majority of the coded segments in this subtheme. These data were illustrative of previous work by Dudas et al.,<sup>43</sup> Ekman et al.,<sup>44</sup> Jones et al.<sup>40</sup> and others, showing the value of active listening in establishing patient goals. Decisions about activities of daily living and the additional activities required by the heart failure regimen require a mutual understanding between professionals and patients. The present study is consistent with previous studies suggesting that patients wish to engage in ongoing, often repetitive discussions regarding the requirements of the regimen in everyday life, and yet, information delivery in the traditional form is not commensurate with improved patient self-efficacy or comprehension.<sup>45</sup> For example, when the effect of consistently and carefully listening to patients about daily life with chronic heart failure is evaluated, and professionals and patients make health plans and decisions together, results demonstrate reduced hospital stay, improved discharge processes, increased personal belief in one's self (self-efficacy), and reduced uncertainty about the condition and medicines.<sup>42,43,46</sup> In addition, patients with low educational levels had significantly greater improvements in self-efficacy as compared to more highly educated patients.<sup>40</sup> In contrast, traditional disease management programmes rely primarily on the delivery of information about the condition and treatment, while patients seem to prefer to be able to discuss and be listened to.<sup>48-50</sup> Together these findings suggest that taking time to listen to patients, rather than cursorily instructing and informing, may effectively improve communication between patients and care providers and resolve unmet expectations related to working to be heard.

The findings emphasize the need for providers to recognise patients' *need to know* as an expectation; one which is composed of beliefs in how successful the regimen will be and beliefs in the value and trust embodied in the patient-provider relationship.<sup>41</sup> The present study demonstrates that patients exert a great effort to communicate with health professionals in a way that allows them to get answers that are meaningful for them.

Expectations for goal-setting were evident in these findings and were specifically linked to patients' desires for communication. These data support work by Doorenbos et al.<sup>41</sup> and other authors suggesting that communication must be in place to support the patient and avoid feelings of being 'let down' by the medications. A clear plan for medication-related goals was not established together between the patient and provider, thus successful achievement of medication-related goals was a nebulous, amorphous concept for patients in this study. In contrast, these same patients who subsequently received an intervention to establish meaningful medication-related goals achieved significant improvement in their ability to manage medications effectively over time.<sup>36</sup>

An opportunity exists to facilitate patients' capacity to succeed on their own terms, according to a mutual, shared set of goals for medication taking. However, previous research suggests that patient-physician discordance with regard to the reasons for inconsistent medication taking is prevalent.<sup>15</sup> In previous studies, physicians argued that patients do not understand the importance of taking medicines, while patients described that it is not difficult to understand that you should take your medicines, the difficulty lies in the work of accomplishing this task in everyday life.<sup>15</sup> These findings are replicated in other studies that also illuminate the expectations patients have for repeated, iterative exchange about medications – to improve confidence, allay fears, and reinforce belief in the need for lifelong medication regimens.<sup>36,51</sup>

Patients in the present study expressed expectations for communication that was directed towards and aligned with the skills, resources, capacities and cultural norms of the environment in which they lived. The daily management of medications that they could not afford and that failed to ameliorate symptoms effectively challenged patients. They were willing to do it, but the effort was hard work, and the support for ongoing persistence with medication management was not forthcoming.

These findings underscore the theoretical constructs in meaning response theory regarding understanding and cultural values, and have previously been reported in other patient populations and contexts.<sup>52,53</sup> The majority of the informants in this study represented a socioeconomically disadvantaged sector of society. Although managing illness is recognised as burdensome, necessitating 'hard and heavy work' including the physical, relational

and social acumen required to access information and material resources,<sup>54–56</sup> these needs are not consistently and directly addressed with patients. As a result, existing research frequently shows associations between low adherence and poor outcomes in populations with low education and income,<sup>52</sup> and inequalities in care have been reported to be higher for African-Americans than for white patients.<sup>57</sup> One reason proposed by Street and Haidet<sup>58</sup> suggests that physicians believe that African-American patients have less desire for partnership, and that a significant discrepancy exists between the physicians' perception of patients' health beliefs and the actual health beliefs that patients hold regarding provider partnerships and managing medications in chronic illness. The authors demonstrate that such misperceptions might be overcome with training.<sup>59</sup>

Finally, managing illness and medications requires mobilising and maintaining supportive relationships.<sup>60</sup> In this work of mobilising, the patient requires skills and capabilities to mobilise and maintain relationships. The theoretical constructs of feeling cared for, and caring for self<sup>27–29</sup> are reflected in these findings, and the notion of not 'feeling cared for' may be a reflection that work done in this area has been insufficient. Patients in this study did not, for example, report feeling cared for or supported with regard to providers or the healthcare system in general. Rather, although the patients had family and caregivers, the cumulative skills and capabilities of the network were insufficient, and the training for the relationships to function as 'supportive networks' for the skills and capabilities required for adherence was also insufficient.

The second subtheme of unmet expectations was further specified as resignation to taking medications for life, often with little hope for symptom relief. Unmet expectations that were categorised as resigned commitment were expressed in relation to two distinct aspects of care, resignation to a lifelong commitment to take medications, and resignation to medications as never fully remedying the persistent symptom burden of chronic heart failure.

Patients' active decision-making was further exemplified in this study in the construct of intention. Despite a clear intention to take prescribed medications 'for life', patients' expectations of the medications were repeatedly deflated. Although they were disappointed by the medicines, either from side-effects or no effect at all, patients were surprisingly determined to 'keep trying'. This same conflict between intentions and expectations has also been noted in the health behaviour medical anthropology literature.<sup>61,62</sup> One reason is that the treatment effect fails to meet the expectations of the patients. The implications of the finding are far more telling than occasionally 'forgetting' to take the medicine. Rather, these findings suggest a complex sequence of thought and decision-making; work which patients willingly, but reluctantly and sometimes

begrudgingly, engage in to manage medications, even in the absence of provider-engaged communication or partnership in decision-making.

While treatment effects, which clearly are acknowledged by the patients as desirable, are based on aggregation towards the mean of a group, the challenges of everyday life are not. Our interpretation of the empirical data suggest a strong willingness to reach the 'desired prescribed' treatment outcomes, yet everyday life with the treatment and the illness slowly detaches the 'desired' and replaces it with 'what for, if not for helping me?'

As supported by the meaning–response theory, the concept of expectation is a patient's belief that the regimen will be helpful. Unmet expectations, for example persistence of symptoms despite taking medications, did result in a patient's loss of a meaningful connection with the medication regimen in this study. Expectations that were not met resulted in the perception of medicines as being not easy to live with and not helpful, and as causing more problems than they solved.

This study was limited by the use of baseline interviews that were a part of a larger, randomised, controlled trial.<sup>36</sup> As a result, formal member validation could not be done because of the risk of interference with the course of the trial. Also, the use of probes was limited for this same reason, and the use of post-intervention interviews following the conclusion of the trial was not included in the protocol. Despite these limitations, the data captured from participant perspectives at baseline constitute a rich source of personal experience with medication taking that sheds light on adherence from a new angle.

Clinical implications are three-fold and include: (a) assess expectations for the effects and side-effects of medications; (b) be aware that the relationship between expectation and intention changes over time such that ongoing assessment is needed; (c) acknowledge the work that it takes for patients to manage medications, and support that work over time by documenting and re-addressing shared goals, strengths and resource capacities.

## Conclusions

Patients' expectations of medications changed over time, typically affecting intentions. Expectations changed as symptom relief decreased and frustrations with medications increased, ending in resignation to unmet expectations. This study provides a clear avenue for improving medication adherence by listening carefully to individuals' expectations regarding their medication, and engaging in the sometimes challenging conversations regarding intentions. Through more effective listening, providers may improve collaborative work with patients to establish strategies for living with medicines as one part of a broader set of health goals.

## Implications for practice

- Patient expectations of medications, which are largely unknown, may affect how patients choose to manage medications.
- Patients who screened as non-adherent to prescribed medications participated in semistructured interviews. Of 17 initial themes (223 representative segments), the overarching theme, 'unmet expectations', consisted of two subthemes: 'working to be heard' by professionals and 'resignation' to both the illness and medications.
- Patients' expectations were challenged by unexpected work to communicate with providers in general (72 representative segments), specifically regarding medications (118 representative segments).
- Unmet expectations contribute to poor medication management.
- Improved listening and communication by providers may strengthen patient beliefs, resolve feelings of resignation, and improve patients' ability to manage medications effectively.

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## Conflict of interest

The authors declare that there is no conflict of interest.

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