

**When patients' invisible work becomes visible:
non-adherence and the routine task of pill-taking.**

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When patients' invisible work becomes visible: non-adherence and the routine task of pill-taking

Abstract

While the biographical dimensions of chronic illness have been well researched, studies on the concrete dimensions of patients' work have not been as thoroughly investigated as yet. With the growing concern for self-management, such research would be timely. This study aims to better understand patients' invisible work by highlighting causes of unintentional non-adherence as well as strategies for adherence. For this purpose, it defines medical treatment adherence as the repetition of the pattern of tasks through which a patient succeeds, in a technical sense, in taking the right medication at the right time, in the right amount, for the right duration. Applying a failure modes and effects analysis (FMEA) approach to 48 semi-structured interviews with Dutch patients, it evidences the negative impact of schedule changes, pressure, positioning changes, lack of backup pills and lack of verification tools. Symmetrically, it highlights the role of anchoring sequencing, positioning, cueing, correcting and verifying. This result points to the need for an analytical approach of patients' work and treatment adherence that would build on the role of routines in organisations and in the workplace.

Anselm Strauss and Juliet Corbin (Corbin & Strauss 1985) (Corbin & Strauss 1988) have made a decisive contribution to the analysis of chronic illness by highlighting that the experience of living with a chronic condition entails a certain amount of work in relation to this condition. This "patients' work" includes three main types of work: illness work (symptom management, and crisis prevention and management), everyday-life work (tasks that need to be done on a daily basis, such as self-care, employment, or looking after children), and biographical work (reconstructing one's biography). The overarching concept of the patients' work is fundamental because it has shown that chronic illness has a social dimension, which is important to understand in order to meet the needs of the patients and those of their relatives (Conrad & Bury 2008). Along with other classical concepts, this vision of chronic illness has helped deepen the understanding of patients' experience of this type of disease, and in particular its biographical dimension, be it in terms of biographical disruption (Bury 1982), loss of identity (Charmaz 1983), or meaning of illness (Williams 1984). Although these instrumental insights have been refined as new studies were carried out, they have shaped a relatively homogenous strand of research, whose major theme could be called "threat to identity" (Armstrong 2003). This particular thread is still running through most works dealing with chronic illness, probably because it points to a key dimension of people's experience.

By comparison, studies on the more practical and concrete dimensions of patients' work have not built such a coherent corpus as yet, although this would deepen our understanding of what chronic illness entails and thus help better meet the patients' needs . A concern for self-management (Schulman-Green et al. 2012) has recently elicited more interest fo these dimensions . Indeed, chronic illness and its treatment are by definition long-term matters that require people to be active, which means that chronic patients must reorganise their daily lives in a way that integrates the illness and its management. Some studies have explored different aspects of time in chronic-illness management. They have shown that self-management requires that patients negotiate with themselves and establish priorities, including the allocation of time between everyday life and illness (Townsend et al. 2006); that medication-taking involves a three-way alignment between the inner experience of time, standardised clock time, and the requirements of the medication schedule

(McCoy 2009); or that the continuity of care calls for personalised management strategies, in particular during the most acute phases, in a context where care can be discontinuous or uncoordinated (Jowsey et al. 2016). These studies have focused on the strategies used by the patients when facing multiple demands. They have examined more closely the material and organisational resources patients mobilise to manage the time-related aspects of the illness. They have thus reintroduced a highly sociological dimension in the analysis of chronic illness, by underlining that the related conditions have their own temporal rhythm and intersect with the rhythm of other daily activities and demands. This dimension could be just as specific for chronic illness as that of “threat to identity”.

This interest in the patients’ work and its temporal dimensions seems fruitful in analysing non-adherence, in line with the study conducted by Liza McCoy (2009) on the time work patients had to perform in order to “do” adherence. Treatment adherence is often approached from a normative perspective, even if it is now well established that patients may have rational reasons to behave in a non-adherent way (Donovan & Blake 1992). We suggest that it is possible to have a non-normative approach to treatment adherence while still focusing on adherence and non-adherence as such. Indeed, going further in the analysis of the work of patients, non-adherence can be conceptualised as a discrepancy between the task that had been prescribed and the task that has been actually performed, and not as a medically deviant behaviour. Such an analysis could help not only to improve our understanding of the experience of chronic illness but also to address new aspects of medication practice (Conrad 1985). In particular, focusing on the practical work and tasks to be performed daily by patients would answer the criticism that studies on non-adherence focus primarily on patients’ beliefs and overlook the extent to which these beliefs are shaped by the concrete dynamics of patients’ lives rather than actual reflection alone (Rosenfeld & Weinberg 2012).

In this respect, unintentional non-adherence is particularly interesting, because it is less likely to be caused by a decision and more likely to be caused by some elements in the complexity of patients’ lives or by the organisation of illness work. This is supported by the fact that it is not uncommon for studies aiming to identify factors for non-adherence to evidence those that lead to intentional non-adherence (such as beliefs, perception of side effects, or the perception of clinical improvement), but to fail completely to identify those for unintentional non-adherence (Iihara et al. 2014) (Meghani & Bruner 2013). Many studies mainly evidenced forgetfulness (Khan et al. 2014) or pointed to differences in terms of socio-demographic characteristics of the patients (Wroe & Thomas 2003) (Efficace et al. 2014) (Gadkari & McHorney 2012) (Park et al. 2011) (Wroe 2002). The studies that evidenced other factors provide a scattered picture. Some beliefs seem to play a role, such as medication beliefs (Griva et al. 2012) (Gadkari & McHorney 2012), concern beliefs (Unni & Farris 2011) (Clifford et al. 2008), overuse beliefs (Schüz et al. 2011), or a lower belief in the necessity of the medication (Rees et al. 2010), while health literacy (Lindquist et al. 2012), perceived self-efficacy (Wouters et al. 2014), or treatment-related issues such as practical problems (Wroe 2002) (Wouters et al. 2014) or doctor–patient communication (Wu et al. 2015) also seem to be involved in unintentional non-adherence. If it is relatively easy to suggest reasons why people may refuse to do a particular thing, as is the case with intentional non-adherence, it is more difficult to hypothesise why people may be unintentionally brought not to act as they know they should, as is the case with unintentional non-adherence. Most studies tend to consider three main cognitive or practical dimensions for unintentional non-adherence: forgetting (Khan et al. 2014) (Gadkari & McHorney 2012), practical barriers (Gadkari & McHorney 2012) (Wroe 2002) (Wouters et al. 2014), and being careless (Gadkari & McHorney 2012). However, these dimensions are not satisfactory, because it remains to be explained why people would forget or be careless about their treatment, and why they would fail to anticipate those practical barriers or face them on a regular basis without being able to remove them.

Recently, more sophisticated causes, based on psychological concepts, have been

suggested and evidenced. Prospective memory, i.e. the ability to remember that an action will have to be performed in the future, seems to be involved (Lam et al. 2013). Similarly, habit strength is predictive of unintentional non-adherence behaviour (Alison Phillips et al. 2013). These results are supported by empirical studies investigating the patients' perspectives. They showed that, according to the patients, unintentional non-adherence relates to changes in their routines (Wu et al. 2015) and that the stability of routines is important for treatment adherence (Chambers et al. 2011). However, these studies did not investigate routines as such. They evidenced that variations in them are sometimes the reason for forgetfulness. But routines are not only a matter of cognition. They are concrete and multifaceted. They connect tasks with places, people, tools, time, or activities. This perspective is interesting because it opens a new direction for investigation, beyond forgetfulness and carelessness. Adherence can be viewed as a routine set of tasks, in which beliefs, decisions, and judgement are relatively unimportant once the routine has been established. Indeed, treatment adherence implies tasks that all have to be carried out in the same order on a regular basis, because a specific amount of a specific drug has to be taken at a specific time of the day. Thus, treatment adherence is part of the important but invisible work that patients perform, in particular when they have a chronic illness (Corbin & Strauss 1988). Reintroducing the dimension of work and focusing on the patients' work, in line with classical studies on the sociology of chronic illness, allows a connection to be made to the sociology of work and to organisation studies.

This study aims to better understand patients' invisible work by evidencing causes for unintentional non-adherence. For this purpose, it addresses pill-taking as a process and defines medical treatment adherence as the repetition of the pattern of tasks through which a patient succeeds, in a technical sense, in taking the right medication, at the right time, in the right amount, for the right duration. Unintentional non-adherence is a failure, in a technical sense, in this process of repetition, be it by taking the wrong medication, or at the wrong time, in the wrong amount, or not taking it at all. This study suggests that an unintentional disruption in the pill-taking schedule may have five causes that often interrelate: a change in the daily schedule; a particular pressure on the performance of daily tasks; a change in the usual spatial organisation; the absence of a backup pill to remediate the consequences of the aforementioned causes; and the absence of a verification device to check if the pill was actually taken or not. These causes highlight the considerable amount of work that patients with a chronic illness perform when doing adherence and maintaining regularity and accuracy in pill-taking.

2. Methods

This study is based on 48 semi-structured interviews conducted in a public hospital in the Netherlands in 2014 with patients suffering from diabetes mellitus type 2, hypertension, Parkinson's disease, inflammatory bowel disease, or chronic myeloid leukaemia who had been prescribed a medication for a chronic disease for at least one year. The conditions were selected in order to have a sample of contrasting situations with respect to treatment and medication practice and to factors that influence them. Some often involve doctor-prescribed lifestyle changes in addition to pill-taking (diabetes and hypertension), others often involve patient-chosen lifestyle changes (inflammatory bowel disease), others involve none (Parkinson's disease and chronic myeloid leukemia), and it is known that whether a treatment regimen is circumscribed or not is important (DiMatteo 2004). Some conditions react to treatment in a way that cannot be monitored by the patients themselves (chronic myeloid leukemia), others can be monitored by the patients themselves on the basis of their own bodily perceptions (Parkinson's disease, inflammatory bowel disease), and others can be monitored by the patients themselves on the basis of their own bodily perceptions or of specific devices (diabetes and hypertension). Some conditions have acute phases (inflammatory bowel disease) or an acute onset (chronic myeloid leukemia, sometimes hypertension), and it is known that both the modes of perception of the illness and its critical phases play a role in medication practices (Conrad 1985).

The Institutional Review Board/Independent Ethics Committee of the Máxima Medical Centre declared that this study did not have to be reviewed by a medical ethics board according to Dutch Law on Medical Research with Humans (WMO). Each interviewee's informed written consent was recorded. Outpatients were contacted by a research nurse or a physician. They were randomly chosen: the patients were asked some time prior to a scheduled appointment if they would accept an interview in addition to their medical appointment. The first patients who did accept to participate were included. No patient declined to take part. The interview guide addressed the patient's medical history, how the medical treatment was integrated into daily life, the way the patient's personal experience of the illness related to the medical staff's professional knowledge about the disease, and illness and treatment disclosure. The interviews were recorded and fully transcribed.

Interviews were conducted with 26 men and 22 women; 16 had type 2 diabetes, 6 had both type 2 diabetes and hypertension, 8 had hypertension, 11 had inflammatory bowel disease, 5 had chronic myeloid leukaemia, and 2 had Parkinson's disease; 21 of the respondents were over 66 years, 17 were aged 50 to 65 years, 7 were aged 30 to 49 years, and 3 were less than 30 years old. Among these respondents, 33 were married, 5 were cohabiting, 4 were single, 3 were divorced, and 3 were widowed; 9 had completed primary education or advanced primary education, 22 had completed secondary education, and 17 had completed advanced secondary education or higher education. These interviewees have a range of backgrounds and family situations that make the interviews diverse enough, while these socio-demographic characteristics are not different from those of the patients' population.

Investigating the causes for unintentional non-adherence is methodologically challenging for qualitative research, because of the unintentional dimension of the phenomenon. Conventional coding methods, and in particular Grounded Theory, focus on the meanings that the interviewees attach to their experience. They proved especially useful to analyse how the patients interpret their illness experience, and in particular the threat this experience poses to their identity (Armstrong 2003). But it is reasonable to infer that it is extremely difficult to attach a meaning to something that is not intentional. For this reason, instead of conventional coding, the research was informed by the method of failure modes and effects analysis (FMEA) (Franklin et al. 2012). This method is used in engineering and more specifically quality engineering, including quality engineering with respect to safety hazards (Lux et al. 2016) or with respect to human mistakes (Hertig et al. 2016). It is used for identifying all possible failures in a design, a manufacturing or assembly process, or a product or service. It can be used for different purposes, including analysing failures of an existing process. It addresses a particular function in a process, a product, or a service and aims to identify potential failure modes, potential effects of the failure, potential causes of failure and their occurrence rate, the current process controls and their detection rate, recommended actions to lower occurrence or severity of failures, and the results of these actions. In our study, the "function" was for the patient to take the amount of the medication prescribed by the medical professional at the right time. "Failures" were any unintentional departures from this pattern of tasks. Although this description may seem more machine-oriented than human-oriented, it proved analytically useful, precisely because it is very well suited to the analysis of the patients' work. It allows a rigorous and complete understanding of the tasks patients have to perform when taking their medication, and it is thus actually truly patient-centred. Thus, this method made it possible to identify a set of strategies that the interviewees would find difficult to describe, because they considered them self-evident, insignificant, not even worth mentioning and they were often hardly conscious of using them. An approach based on the meanings the interviewees' attach to these strategies would therefore have been inadequate.

We adapted and used FMEA in a simplified way, as follows: first, all the accounts of unintentional non-adherence reported in the interviews were identified (i.e. each account of an unintentional departure from the prescription, either regarding the medication itself, the amount of

the medication, the time when it was taken, or the way to take it); second, these accounts were coded and sorted out according to the cause of the non-adherence; and third, the labels were cross-checked in a blind manner by a second researcher, and differences were discussed until agreement was reached on the final coding. Then, the elements that the patients usually build on to avoid such unintentional departures were investigated more precisely, and the corresponding strategies were identified.

3. Findings

Among the 48 interviews, 8 contained no account of non-adherent behaviour at all, 21 interviews contained at least 1 account of intentional non-adherent behaviour, and 28 interviews contained at least 1 account of unintentional non-adherent behaviour (10 interviews contained both accounts of intentional and unintentional non-adherent behaviour, and are therefore counted in both groups). In the 28 interviews containing accounts of unintentional non-adherence, there was a total of 46 such accounts: in 6 it was not possible to precisely determine the cause of the behaviour (the respondents simply said they forgot), whereas 40 provided enough information to describe the cause of the failure. These data evidences five causes that will be presented separately for analytical purposes:

- a schedule issue;
- a pressure issue;
- a positioning issue;
- a backup issue;
- a verification issue.

These causes relate to a range of adherence strategies, namely anchoring, sequencing, positioning, cueing, building redundancy, and verifying.

3.1 A schedule issue

A schedule issue was the most common cause of unintentional non-adherence in the interviews, with 15 accounts. The interviewees described how a change in their daily schedule made it difficult for them to take their pill as usual. This was well illustrated by this 55-year-old man who has inflammatory bowel disease (Patient 45):

Question: And when do you happen to skip a day?

Answer: It's often because of another rhythm. On holidays. Hmm. Yes, sometimes during the weekend, because I do other things. And sometimes, at midday, I think: oh, wait, I must take my medications. I haven't taken them yet today; I have to do it.

In the interviews, this change referred to a different pattern of activities recurring regularly (e.g. weekends, holidays) or irregularly (e.g. a day trip, a family gathering).

A closer look at how the interviewees usually take their pills suggests that they tend to anchor pill-taking in another pre-existing daily routine (such as having breakfast or going to bed). Of the 48 interviewees, 33 mentioned such an anchoring strategy. The schedule issue appears when this daily routine is disturbed, be it because it falls apart or has to be performed earlier or later than usual. This was described by this 67-year-old man who has hypertension (Patient 30):

Question: Do you have some particular tricks to help you?

Answer: Yes, it's always the same ; it's a part of my breakfast. And I forget when for any reason I do not have breakfast. That does not happen so often. Then I have to put the alarm clock on to take them later on... because I always swallow them with my meal because I was told that it is the best time.

In one case, the patient, a 31-year-old woman with hypertension, explained that she used to have no anchoring strategy at all, and adherence was extremely difficult to maintain (Patient 31):

Then I forgot those pills very often. And I thought: oh yes, I have to take those things.

You see, just like that. To the extent that [the doctor] had to say something like this: you

must really plan the appointments with yourself now, that time and that time. Otherwise you forget about it. Because that's what I did, and so my blood pressure went up, down, in all directions.

Several interviewees said anchoring was easier to maintain in connection with a morning routine, less easy with an evening routine, and could be difficult with a midday routine. Interestingly, the issue for them consists in integrating pill-taking into their daily schedule and making it a fully-fledged part of their daily activities, and not on aligning pill-taking with clock time.

3.2. A pressure issue

A pressure issue was mentioned in 11 accounts. The interviewees mentioned that a particular pressure (6 interviewees), stress (1 interviewee), or hurry (1 interviewee) led them to "forget" to take their pill. This was well illustrated by this 52-year-old man who has diabetes (Patient 11):

Question: Can you compare the pill-taking routine with your other daily routines?

Answer: Yes, it's integrated into them. And I see it when those daily routines change, then pill-taking changes too. Because if you have a stressful day and you're... And pressure here, pressure there, and then you will not eat for lunch. Well, that all has an impact. [...] And when you get home late at night, then [the time when you usually take your pills] is over, and you're tired and then you drop everything and you go to bed. And then you lie in bed and then you think: yes, hmm. Well, I'm not really going downstairs to take a little pill.

It must be noted that although this interviewee mentioned the schedule issue, the change in the routines is in this case a result of the pressure at work. Without this pressure, the usual routines would be carried on. Thus, contrary to the situations described in the previous section, there is no schedule change as such in the first place.

A closer look at what the interviewees said about this pressure suggests that its negative impact on pill-taking is twofold: it may prevent anchoring, and it may disturb the usual sequence of actions that supports the integration of pill-taking with other routines.

Pressure may indeed be so strong that time is lacking to perform all the actions the patients have to perform. They thus skip some of those in which pill-taking is usually anchored, as described by this 68-year-old woman who has diabetes (Patient 22):

And in the morning, the first thing I do is wash, dress, and go downstairs and then we take a cup of coffee. And the pills belong with the coffee, immediately. [...] That's my routine in the morning. And then I start the rest. [...] Sometimes I'll skip breakfast too, but that's not that smart. But well, it may happen. If it has to be fast, if I'm really late, then I will leave straightaway.

As for the previous excerpt, the schedule change is a result of the pressure the interviewee experienced.

Pressure may also disturb the usual sequence of actions that constitute a daily routine, remove parts of this sequence, and in particular pill-taking, but without removing the anchor as such. Many interviewees stated that they insert pill-taking between two specific sequences of actions that constitute the anchoring routine, such as opening the cupboard and taking the cutlery out for breakfast. This is what was suggested by this 27-year-old woman who has inflammatory bowel disease (Patient 40):

Question: Do you find it easy or difficult to stick to [pill-taking]?

Answer: Well, sometimes I find - especially on the days when you... suffer from your belly - you will take the medication ahead of time because you know it will help. If you do not suffer and you have a busy morning, or whatever in the morning - and I'm a midwife, so sometimes you have to leave earlier - yes, then it sometimes falls apart.

So...

Q: But then it's really forgetting?

A: At that moment, it's just forgetting because of the pressure. Then I'll take it in the evening. Then I think: Oh yes, this medication. Because it is in the cupboard in the kitchen, so when I open it to take my cutlery, I see it.

This third excerpt also points to the spatial arrangement of the daily routines. Examining this arrangement for pill-taking failures and strategies is the purpose of the next section.

3.3 A positioning issue

A positioning issue was mentioned in 3 accounts. The interviewees said that a change in the positioning of their treatment led them not to take one or several pills. Although this is not a common cause as such for a disruption of the pill-taking routine, it is an important one on the analytical plane, because it sheds light on how spatial arrangements contribute to the reliability of the pill-taking process. This is apparent in the situation described by this 67-year-old man who has hypertension (Patient 30):

The one time I forgot to take [my medications on a journey] was when I had to travel to England for 4 days. And... then I did not take them for 4 days. I also said to the doctor - it was the cardiologist - I said: does it do harm? Well, he said: yes, you should in any case take the medication against high blood pressure every day. [...] but well, that happened only once.

Q: Were you frightened then?

A: Well, because I'm so steadfast, I thought that was, eh... I'm quite disciplined in that, so it was a worry. Yes. I really thought, damn, I usually care so much. But the funniest was when I found out that I actually had them with me. I had only put them in another place in my suitcase (he laughs). What I never do. Normally I always put them in my toilet bag.

The positioning issue rarely appears so clearly, because it is often connected to a schedule issue. However, this excerpt highlights that the positioning issue is distinct. Had this interviewee put his pills in their usual place, the other changes resulting from the journey would have been harmless.

A closer look at how the interviewees usually take their medication suggests that positioning is a key component of anchoring strategies and also of cueing strategies. Seventeen interviewees mentioned that their medications had a particular location and that this location was instrumental for the pill-taking process.

For most interviewees, anchoring indeed implies that the location of the medications to be taken fits into the setting of the anchoring routine. To achieve this, the interviewees described how they put their medications in a very visible place in the setting of the anchoring routine (for instance, on the nightstand if the anchoring routine is "going to bed") or, more strategically, they position their medications in a place that makes them unavoidable when performing the anchoring routine. This is what was described by this 57-year-old man who has hypertension and takes his medications at breakfast (Patient 26):

Question: Do you have some particular tricks to help you?

Answer: [...] When I come downstairs in the morning, on the corner of the counter [in the kitchen] stands the coffee machine. In the box above [the coffee machine] are the sugar and the milk and there are also my medications. In that same box.

In some cases, positioning may be used instead of a routine to anchor pill-taking, in particular when the medications have to be taken at times that do not fit easily with existing routines. A visible and strategic location for the medications will provide the cue for pill-taking and thus play the role otherwise attributed to the anchoring routine. This is the case for this 69-year-old man who has Parkinson's disease and needs to take medications during the day between meal times

(Patient 10):

Q: Then you have to think of [your pills] 4 times a day. Does it cause problems when you're on holidays?

Answer: Well, at times, there are even problems at home, because actually, yes, occasionally, I lose track. But in the morning when I get up, I have that Madopar, then I have breakfast, and then I start with my medications. [...] I take the first one, and I put the other one in a pot on the corner of the counter, I add 2 apples, which I will have during the day, and then I do the same thing again. I also add 2 more [...]. And I put those in a box in a place where I have to come back to get my food in the evening, in that box. Yes, otherwise I will forget it.

The strategic positioning of the medications thus appears to be an essential component of the pill-taking process. This may explain why it is rarely the only cause for a disruption of this process, and why it is on the contrary often briefly mentioned in connection with a schedule issue (for instance when the interviewees are away on holiday) or with a pressure issue (for instance when some actions are skipped, thus transforming on a small scale the spatial arrangement of the day, such as having breakfast and therefore going to the kitchen). This may also be the reason why some interviewees have developed strategies to make sure that they always have their medications with them, which is the fourth issue with unintentional non-adherence.

3.4. A backup issue

A backup issue was mentioned in 8 accounts. The interviewees mentioned that they noticed after a couple of hours that they had not taken their pill at the usual time, but they were unable to correct their mistake because they had no backup pill with them. This is how this 68-year-old woman who has diabetes and hypertension described it (Patient 22):

Well, I'm doing something and I think: oh yes, I should have taken my medications!

But, they are lying there; I do not always have them with me. I do not run around all day with pills in my bag. Then I forget them. And then I think: yes, I'll do that later. And instead of 4 o'clock, it will be 6 o'clock. And then I think: well, hmmm, 6 o'clock, I do not take them anymore.

This situation may relate to some extent to a schedule or a pressure issue because such an issue may be what had initially caused a pill to be skipped, although the interviewee does not mention it. But it also points to a distinct phenomenon. Had this interviewee had a backup pill with her, she would have been able to solve the problem immediately. Thus, the key element that eventually determines whether there will be a failure in the adherence process is the unavailability of this backup pill.

A closer look at how the interviewees usually take their pills suggests that what several interviewees termed "building safety" is a fully fledged part of their adherence strategies. Thus, 15 interviewees explained that they pay attention to always having one pill with them (in their handbag, their wallet, etc.), or to take extra pills when they go on holiday. This is how this 63-year-old woman who has hypertension described it (Patient 32):

Question: And how often do you forget?

Answer: Yes? 1 or 2 times a week. And then I nevertheless have [my pills] with me in a bag. So I think: oh, drat, I've forgotten! And then I simply have them with me.

Q: And you take them immediately?

A: Yes. I take them immediately.

This strategy parallels that of redundancy in engineering, i.e. the inclusion of extra components that are not strictly necessary to functioning but are there to act as a substitute, in case of failure in other components. The fact that a pill was missed can often be remedied, provided a backup pill is at hand. On the contrary, not planning to be able to turn to this backup pill will result in non-adherence.

3.5. A verification issue

A verification issue was mentioned in 2 accounts. The interviewees said that they were not sure whether they had taken their pill but they had no means to check this. This implies that, had they actually forgotten to take it, they had no means to correct their mistake and there would be a failure in the adherence process. This is what was described by this 41-year-old woman who has hypertension (Patient 31):

But if I simply have a day out or go to a party, then I may skip [a pill]. Or think, did I take it actually or not? And then you can say that you can see that on the medication strip, but I can't, because I forget – I'm quite forgetful - eh ... I do not know anymore if I already had one or still have one left or if I'm about to take a double dose. Then I think: I stay safe ; I don't take it now. And I'll take it tomorrow (laughs).

The doubt was cast by a schedule change (holidays or a gathering) that may have or may not have resulted in a skipped pill. As for the backup issue, this change creates a situation that pushes towards non-adherence, but that is not sufficient to result in it: had the interviewee had a means to make sure that the pill had not been taken, she could have corrected her mistake by taking it, thus avoiding a failure in the adherence process.

A closer look at how the interviewees usually take their pills and other treatments (e.g. injections, drops) suggests that verifying that the treatment has been taken properly is part of their adherence strategy. Thus, 11 interviewees explained that they had developed some techniques to help them see if they had forgotten an element of their treatment or make sure they had taken it. This is what this 62-year-old woman who has hypertension and diabetes said (Patient 33):

Question: Do you perhaps have special tricks [to help you remember]?

Answer: Well, every Sunday morning - I have a box, for every day - and on Sunday mornings I fill it. So once I have eaten, I take that box out of the cupboard. And if I ...

Yes, I have two boxes, one with what I have to take in the morning and in the other box, there are my pills for the afternoon and the evening. And the box for Because the boxes are in the cupboard, one behind the other, and when I have to take my pills in the afternoon I have to take the front box, because I put the other one behind. And then: Hey? I haven't had them this morning? How is that possible?

Q: Then you see it immediately and then you can correct it?

A: Yes. Yes.

Some interviewees developed more personal strategies, such as this 63-year-old woman who has hypertension (Patient 32):

But in general I drink a bottle of [cholesterol-lowering yoghurt drink] every morning. I find it tasty. So I combine it with my pills. So I know simply: oh yes, fine. And when there is the [empty] bottle on the counter then I think: oh yes, I have had my medications.

These strategies rely on a spatial arrangement that facilitates the integration of the verification step into the sequence of actions built upon a main routine. They parallel industrial or workplace reliability techniques whereby operators automatically check that a whole procedure was performed as planned. In the case of adherence, these techniques are to some extent idiosyncratic, because they are based on the daily routines of individuals.

4. Discussion and conclusion

These results go beyond the characterisation of unintentional non-adherence in terms of forgetfulness, carelessness, or practical barriers. They evidenced that unintentional non-adherence occurs when a range of routine-based strategies are challenged (anchoring, sequencing, positioning, cueing) or when reliability-supporting techniques are missing (redundancy and verification). This is in line with the idea that treatment adherence is something that has to be “done” by the patients

(McCoy 2009), and in the case of a chronic illness, this task has to be performed every day, in spite of competing external demands, and across changing time structure and changing settings (Jowsey et al. 2016).

The use of the FMEA method proved important to fruitfully analyse the concrete and practical matters pertaining to treatment adherence and unintentional non-adherence, and not only focus on patients' beliefs or perspectives, as is often the case with conventional coding methods, and in particular with Grounded Theory. Shifting the focus and addressing the concrete dimensions of chronic illness improves our understanding of the patients' situation and of how these concrete dimensions shape their illness experience, thus answering a major criticism (Rosenfeld & Weinberg 2012) of the studies on non-adherence.

This study contributes to the research on the temporal dimensions of chronic illness by highlighting the importance of the invisible work that goes into building and maintaining a treatment routine, i.e. a frequently repeated actions sequence (Cohen & Bacdayan 1994). For the interviewees, pill-taking did not necessarily have to be performed at a fixed time, contrary to what other studies suggested (McCoy 2009) but it had to be anchored and inserted in the sequence of actions and in the corresponding spatial arrangement that turn it into a routine, and assure reliably that the action is performed during the appropriate time window. This time window is rather broad (typically connected to a meal), and not a single point in time. This involved developing a range of strategies and techniques to make sure they perform their treatment routine in an effective and reliable way.

These results are consistent with other studies that focused on the importance of routine management in treatment adherence (Chambers et al. 2011) (Wu et al. 2015). However, these results go further by evidencing six inter-related strategies that support treatment adherence and contribute to its reliable routinisation: anchoring, sequencing, positioning, cueing, building redundancy and verifying. To our knowledge, this set of strategies had not been evidenced so far. The FMEA method appeared especially useful here, because it revealed strategies that the patients commonly use but that they would generally not be able to describe as such. Contrary to other strategies, such as using exogenous devices to signal pill time or to keep track of the pills that have been taken (McCoy 2009), these strategies do not call for specific medical tools, they were often created without much particular thinking, and they seemed so natural to the interviewees that a particular method was needed to make them visible in the interview process. This was all the more important since these inconspicuous strategies the interviewees were somewhat unaware of were much more frequent and significant regarding treatment adherence than device-based strategies.

Second, these strategies point to the *social* dimension of medication adherence and to the complexities of patients' work. It is worth underlining that up to six different and specific strategies appear to be needed together for a single pill to be taken reliably each day. An accurate description of these strategies is important both for conceptual and practical purposes. For patients, the main issue is indeed not a cognitive one, namely that of remembering to do something, although they do talk about it in terms of forgetting or remembering. When people follow their routines, they do not pay attention to them, and they do not need to make decisions about what they are doing or remember anything. Some interviewees said "I do not think about it and I never forget". People are then effective precisely because their actions are routines. Thus, for the patients, the main issue is to find a reliable way to perform this particular task in a complex and changing setting. This focus on routine and reliability contributes to a new conceptual approach for the analysis of chronic illness to the extent that it shifts the focus from that of illness experience and the work of aligning this experience with patients' life experience in general (Armstrong 2003, McCoy 2009) to the issue of the concrete working out of reliable routines. Some dimensions of this reliable routine performance behaviour could be further investigated, in the light of the sociology of work and of the sociology of organisations, in order to better understand and meet the patients' needs.

The temporal and spatial organisation of the pill-taking routine often involves a

considerable amount of invisible work because it is the result of a learning process. This raises the issues of the competences required by the patients to achieve this organisation, of the learning process that led to it (e.g. abstract reflection, trying, and correcting errors), and of the resources that were used (e.g. professional advice, personal advice, support groups, and technical tools). At another level, it also raises the issue of the biographical work that goes into this routinisation of pill-taking, i.e. the micro-integration of the illness deep into patients' everyday lives. This too raises the questions of the skills mismatches, the obstacles encountered by the patients, and the lack of commitment or skills on the side of the healthcare professionals to ensure that patients are able to perform the task they had entrusted to them.

To our knowledge, the issue of the personal cost of implementation of routines has not been studied with respect to treatment adherence. A routine is indeed similar to an investment: setting it up takes time and work, but once it is there, the action can be performed smoothly, in a time- and effort-saving manner. Thus, the patients who have to take a complex treatment or whose daily lives are irregular are not careless or forgetful. The interviewees in these situations did think of their treatment, probably more than the interviewees who followed a medication-taking routine. However, the interviewees who said that they tended to frequently and unintentionally skip some pills had not dedicated time and effort to building up a routine. When a treatment regimen is complex, setting up an appropriate routine is a demanding task. The patients have to devise how to anchor, sequence, position the routine in a effective and robust way, but also how to correct their mistakes with backup and verification techniques. The prospect of performing it alone may discourage many patients. Changes in time structure lead to a similar phenomenon because finding a routine for weekdays, weekends, and holidays is challenging and may be difficult for the patients to achieve on their own. This is why studies paying attention to concrete details of the medication-taking routines and their failures would be needed and would be essential to really incorporate the patients' perspectives and fully understand their experience.

For this purpose, it is worth underlining that the results presented here can be connected to three key results of the studies that investigated routines in organisation and in the workplace (Becker 2004). First, these studies evidenced that routines are processual. This means that they are both stable, because they are anchored in some specific activities, and flexible, because they have to adapt to external disturbances. Interestingly, studies on routines have shown that when people are under stress, they tend to focus on the routines that they have most often repeated. This may help explain why the interviewees reported sometimes skipping the medication-taking routine in order to be able to carry on with other routines. Second, the routines are context-dependent, i.e. anchored in contexts. They are local and difficult to transpose from one context to another. Medication-taking routines are indeed vulnerable to any change in environment, be it small- or large-scale. Third, the robustness of routines depends on how they were implemented. This inertia is important for two reasons. Studies showed that inefficient routines that are well established will be preferred to a more effective routine that still needs to be implemented, and as building up a routine is a demanding process, people will often avoid engaging in this process if they believe that the situation is temporary. These insights are valuable for future research and a deeper integration of the sociology of work into the sociology of chronic illness.

References

- Alison Phillips, L., Leventhal, H. & Leventhal, E.A., 2013. Assessing theoretical predictors of long-term medication adherence: Patients' treatment-related beliefs, experiential feedback and habit development. *Psychology & Health*, 28(10), p.1135-1151.
- Armstrong, D., 2003. The impact of papers in Sociology of Health and Illness: a bibliographic study: The impact of papers in Sociology of Health and Illness. *Sociology of Health & Illness*, 25(3), p.58-74.

- Becker, M.C., 2004. Organizational routines: a review of the literature. *Industrial and Corporate Change*, 13(4), p.643-678.
- Bury, M., 1982. Chronic illness as biographical disruption. *Sociology of Health & Illness*, 4(2), p.167-182.
- Chambers, J.A. et al., 2011. Adherence to medication in stroke survivors: A qualitative comparison of low and high adherers: Adherence to medication in stroke survivors. *British Journal of Health Psychology*, 16(3), p.592-609.
- Charmaz, K., 1983. Loss of self: a fundamental form of suffering in the chronically ill. *Sociology of Health and Illness*, 5(2), p.168-195.
- Clifford, S., Barber, N. & Horne, R., 2008. Understanding different beliefs held by adherers, unintentional nonadherers, and intentional nonadherers: application of the Necessity-Concerns Framework. *Journal of Psychosomatic Research*, 64(1), p.41-46.
- Cohen, M. & Bacdayan, P., 1994. Organizational Routines Are Stored as Procedural Memory: Evidence from a Laboratory Study. *Organization Science*, 5(4), p.554-568.
- Conrad, P., 1985. The meaning of medications: another look at compliance. *Social Science & Medicine (1982)*, 20(1), p.29-37.
- Conrad, P. & Bury, M., 2008. Anselm Strauss and the sociological study of chronic illness: a reflection and appreciation. *Sociology of Health & Illness*, 19(3), p.373-376.
- Corbin, J. & Strauss, A., 1985. Managing chronic illness at home: Three lines of work. *Qualitative Sociology*, 8(3), p.224-247.
- Corbin, J. & Strauss, A., 1988. *Unending work and care: Managing chronic illness at home*, San Francisco, CA: Jossey-Bass.
- DiMatteo, M.R., 2004. Variations in Patients' Adherence to Medical Recommendations: A Quantitative Review of 50 Years of Research. *Medical Care*, 42(3), p.200-209.
- Donovan, J.L. & Blake, D.R., 1992. Patient non-compliance: deviance or reasoned decision-making? *Social Science & Medicine (1982)*, 34(5), p.507-513.
- Efficace, F. et al., 2014. Profiling chronic myeloid leukemia patients reporting intentional and unintentional non-adherence to lifelong therapy with tyrosine kinase inhibitors. *Leukemia Research*, 38(3), p.294-298.
- Franklin, B.D., Shebl, N.A. & Barber, N., 2012. Failure mode and effects analysis: too little for too much? *BMJ Quality & Safety*, 21(7), p.607-611.
- Gadkari, A.S. & McHorney, C.A., 2012. Unintentional non-adherence to chronic prescription medications: How unintentional is it really? *BMC Health Services Research*, 12(1), p.98.
- Griva, K. et al., 2012. Non-adherence to Immunosuppressive Medications in Kidney Transplantation: Intent Vs. Forgetfulness and Clinical Markers of Medication Intake. *Annals of Behavioral Medicine*, 44(1), p.85-93.

- Hertig, J.B. et al., 2016. Development and Assessment of a Medication Safety Measurement Program in a Long-Term Care Pharmacy. *The Consultant Pharmacist*, 31(2), p.112-118.
- Iihara, N. et al., 2014. Comparing patient dissatisfaction and rational judgment in intentional medication non-adherence versus unintentional non-adherence. *Journal of Clinical Pharmacy and Therapeutics*, 39(1), p.45-52.
- Jowsey, T. et al., 2016. Time to manage: patient strategies for coping with an absence of care coordination and continuity. *Sociology of Health & Illness*, p.n/a-n/a.
- Khan, M., Shah, S. & Hameed, T., 2014. Barriers to and determinants of medication adherence among hypertensive patients attended National Health Service Hospital, Sunderland. *Journal of Pharmacy and Bioallied Sciences*, 6(2), p.104.
- Lam, J.W.S. et al., 2013. Prospective memory predicts medication management ability and correlates with non-adherence to medications in individuals with clinically stable schizophrenia. *Schizophrenia Research*, 147(2-3), p.293-300.
- Lindquist, L.A. et al., 2012. Relationship of Health Literacy to Intentional and Unintentional Non-Adherence of Hospital Discharge Medications. *Journal of General Internal Medicine*, 27(2), p.173-178.
- Lux, A. et al., 2016. FMEA and consideration of real work situations for safer design of production systems. *International journal of occupational safety and ergonomics: JOSE*, p.1-17.
- McCoy, L., 2009. Time, self and the medication day: a closer look at the everyday work of 'adherence'. *Sociology of Health & Illness*, 31(1), p.128-146.
- Meghani, S.H. & Bruner, D.W., 2013. A Pilot Study to Identify Correlates of Intentional Versus Unintentional Nonadherence to Analgesic Treatment for Cancer Pain. *Pain Management Nursing*, 14(2), p.e22-e30.
- Park, Y.-H. et al., 2011. Predictors of adherence to medication in older Korean patients with hypertension. *European Journal of Cardiovascular Nursing*. Available at: <http://cnu.sagepub.com/lookup/doi/10.1016/j.ejcnurse.2011.05.006> [Consulté le mai 31, 2016].
- Rees, G. et al., 2010. Intentional and Unintentional Nonadherence to Ocular Hypotensive Treatment in Patients with Glaucoma. *Ophthalmology*, 117(5), p.903-908.
- Rosenfeld, D. & Weinberg, D., 2012. Domestic practice, situated contingency and adherence to medical directives: A call for research. *Soc Theory Health*, 10(1), p.42-60.
- Schulman-Green, D. et al., 2012. Processes of Self-Management in Chronic Illness: Self-Management Processes. *Journal of Nursing Scholarship*, 44(2), p.136-144.
- Schüz, B. et al., 2011. Medication beliefs predict medication adherence in older adults with multiple illnesses. *Journal of Psychosomatic Research*, 70(2), p.179-187.
- Townsend, A., Wyke, S. & Hunt, K., 2006. Self-managing and managing self: practical and moral dilemmas in accounts of living with chronic illness. *Chronic Illness*, 2(3), p.185-194.

- Unni, E.J. & Farris, K.B., 2011. Unintentional non-adherence and belief in medicines in older adults. *Patient Education and Counseling*, 83(2), p.265-268.
- Williams, G., 1984. The genesis of chronic illness: narrative re-construction. *Sociology of Health & Illness*, 6(2), p.175-200.
- Wouters, H. et al., 2014. Endocrine Therapy for Breast Cancer: Assessing an Array of Women's Treatment Experiences and Perceptions, Their Perceived Self-Efficacy and Nonadherence. *Clinical Breast Cancer*, 14(6), p.460-467.e2.
- Wroe, A. & Thomas, M., 2003. Intentional and unintentional nonadherence in patients prescribed HAART treatment regimens. *Psychology, Health & Medicine*, 8(4), p.453-463.
- Wroe, A.L., 2002. Intentional and unintentional nonadherence: a study of decision making. *Journal of Behavioral Medicine*, 25(4), p.355-372.
- Wu, S. et al., 2015. Lack of congruence between patients' and health professionals' perspectives of adherence to imatinib therapy in treatment of chronic myeloid leukemia: A qualitative study. *Palliative & Supportive Care*, 13(2), p.255-263.