

Personalized medication overview (MijnGiB): insights from patients and (in)formal caregivers after first encounter and after one-month patient use

Part B) Qualitative study

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Summary

The instructions on prescription medication labels are not always well-understood by patients. Consequently, a common cause of medication errors is the (in)comprehensibility of medication information, particularly the prescription medication label instructions. In a previous experiment, we investigated the comprehensibility of prescription label instructions for people who were exposed vs. not exposed to a personalized medication overview and whether an increasing number of prescribed medications had an influence on the comprehensibility of the instructions. The results of this experiment show that the personalized medication overview, My Medication Review, [in Dutch: Mijn Geneesmiddel in Beeld® (MijnGiB)] (See box 1), can support patients specifically for the extra information presented on the overview, which is not presented on the usual-care prescription medication labels; such as warnings and for which complication one should use the medication.

Box 1. What is MijnGiB?

- My Medication Review [in Dutch: Mijn Geneesmiddel in Beeld®] (MijnGiB)
- Offered by the pharmaceutical company Teva since 2019
- A complete paper-version, personalized medication overview
- MijnGiB lists all prescribed medications and includes visual information, which can support patients in their medication use compared to the prescription labels on medication boxes
- MijnGiB overview is now offered as regular care in about 450 pharmacies in the Netherlands
- MijnGiB includes the following information:
 - Name of medication,
 - Prescription medication label text,
 - Moment of intake,
 - The number of tablets per day time,
 - For which condition/disease the medication is used for,
 - Advice and warnings for use,
 - Photos of Teva products to recognize the medication,
 - Pictograms/icons of the instructions for proper use.

The next key step after the experiment, as part of a larger study, was to delve deeper into the opinions and experiences of the users of MijnGiB. The aim of this study was to gain insights into the opinions and experiences of patients and (in)formal caregivers regarding MijnGiB after seeing the overview for the first time, and to assess patient experiences after having used MijnGiB for one month.

General perceptions of patients and (in)formal caregivers on MijnGiB

All in all, patients and caregivers are generally positive about MijnGiB, as for most respondents it contains comprehensible and clear information. As such, MijnGiB can support patients who experience medication changes and those with polypharmacy, the use of multiple medications, especially at an early stage of their medication use journey when patients still have to figure out how to use the new medication and include it in their daily routines. Caregivers have a key role in supporting patients with their medication use, and MijnGiB can be useful in keeping overview of the medication use of their patient(s). The pharmacy also has an important role in giving suitable and tailored information to patients, and MijnGiB can be one of the tools they use for that.

Patients after first time exposure and one month use of MijnGiB

In general, patients were positive about MijnGiB. The patients interviewed used medications on a routine-basis. For these patients, the information on MijnGiB was (mostly) clear and comprehensible. For some patients with many medications, the information on MijnGiB was at times overwhelming (i.e. the quantity of the information). Most of the patients indicated that the pictograms and photos of the medication box and tablets/capsules are helpful in recognizing their medication, while some found them to be unnecessary. The majority of the patients suggested that MijnGiB could be of added value in case of medication changes or uncertainties about their medication use. After a month, only a few patients used MijnGiB. Those who did use the medication overview indicated they used it to check their medication use (i.e. intake moment, medication change). Though the majority who did not use it indicated that their medication use is a routine and checking MijnGiB was not needed.

(In)formal caregivers after first time exposure of MijnGiB

Generally, caregivers were also positive about MijnGiB. All caregivers indicated that the information on MijnGiB is comprehensible. The majority found the pictures and pictograms to be handy and help provide overview. Caregivers also suggested MijnGiB can be of added value when there are medication changes, but also for other caregivers such family and friends, aside themselves, who may support the patient in their medication use.

Implications for practice and research

- Patients with polypharmacy and in the beginning of their medication use journey can benefit from the use of MijnGiB.
- MijnGiB can be helpful in keeping overview for patients experiencing frequent medication switches and changes.
- MijnGiB can be positive for adherence as it can allow for more routinization for patients, who find it difficult to keep overview, in taking their medications.
- MijnGiB may be less useful for patients who already use their medications on a routine-basis for several years.
- Given that informal caregivers often manage medications, they have a vital role in detecting how the medication use of the patient is. In these cases where the patient finds it difficult to keep overview of their medication use, MijnGiB may be a helpful tool for such patients and for their caregivers in supporting their patients to keep overview.
- Pharmacists can help detect whether a MijnGiB overview may be suitable for the patient at the counter (i.e. polypharmacy patients, patients who are in an early stage of their medication use journey, patients who may find it difficult to keep overview of their medication use, like those patients who often encounter medication switches). This should be further investigated.
- MijnGiB could also be a good basis for the pharmacy staff to explain how to take the medication, whereby the pharmacy staff can use the teach-back method to check whether the message has been received well by the patient. This should be further investigated.

Methods

We interviewed patients twice (ten patients for the first interview, and eight for second interview) and ten caregivers once. In the first interview with patients and caregivers we assessed their opinions and expectations with regards to MijnGiB. In the second interview we checked whether these expectations had been met and whether the overview had helped patients and in what way.

1 Introduction

Prescription medication label instructions are not always well-understood by patients (1-10). A common cause of medication errors is the (in)comprehensibility of medication information, especially prescription medication label use instructions (3). Problems understanding medical information seem to be more common in certain patient groups, for example the elderly and people with low health literacy (11). People may, for example, not fully understand the use instructions on the label or they do not really know which medication they use for what and why. Low health literacy skills are associated with non-adherence, poorer health, medication errors, hospitalizations and higher medical costs (12). It is therefore important to support patients in understanding health information, including information on how to use their medication.

As part of a larger study, we conducted an experiment (Part A) where we explored how a personalized medication overview listing all prescribed medications and including visual information, My Medication Review, in Dutch: Mijn Geneesmiddel in Beeld® (MijnGiB), can support patients in their medication use compared to the prescription labels (See Figure 1). In this experiment we investigated the comprehensibility of prescription label instructions for patients who were exposed versus not exposed to MijnGiB and whether an increasing number of prescribed medications had an influence on the comprehensibility of the instructions. Based on the results of the experiment, MijnGiB can help patients in their medication use, specifically extra information presented on the overview, which is not presented on the prescription medication labels; such as usage advice and for which complication one should use the medication. A key next step (Part B) based on the results of the experiment was to delve deeper into the opinions and experiences of the users of MijnGiB as the experiment was a fictional situation.

Figure 1. Mijn Geneesmiddel in Beeld® (MijnGiB)

| Pat. No.: | Name: | Name pharmacy | | | |
|-------------------------|----------------|---|---|------------------------------------|--|
| Produced on: 13-07-2021 | Date of birth: | Questions? Call us on: | | | |
| Packaging image | Product image | Label text | Morning After noon Evening Before bed time | What is it for? | Indications for proper use |
| | | <p>1 x PER DAY 1 TABLET, in the morning 2 x PER DAY 2 TABLETS, in the afternoon, in the evening 1 x PER DAY 1 TABLET for the night Watch out with alcohol May reduce responsiveness May discolor urine or stools When to take levodopa? See Apotheek.nl</p> | 1 2 2 1 tablets | In case of Parkinson's disease | No alcohol Can discolour urine or stool Reduces responsiveness |
| | | <p>1 x PER DAY 1 CAPSULE Swallow whole, do not chew</p> | 1 capsule | For heartburn | Swallow whole |
| | | <p>1 x PER DAY 1 TABLET take with water Go to the doctor in case of sudden unexplained muscle pain, Take in the evening</p> | 1 tablet | For cholesterol | Take before sleeping |



This medication overview has been compiled with great care. It contains data known to this pharmacy and therefore need not be complete. As a medicine user, you also have the responsibility to inform your pharmacy about your medicine use. The pharmacy and Teva Nederland are not liable for any errors in this medication overview, except in the case of intent or gross negligence. Mijn Geneesmiddel in Beeld is made possible by your pharmacy in collaboration with Teva Nederland BV. V1.4521 TEVAS-NL-NP-00018



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While patients might use information on medications independently and without support from others, they might also rely on others for this support, more notably their informal and formal caregivers. Long-term care continues to shift from institutional care to home and community options whereby family members and (in)formal caregivers play a role in the increasingly complex care of patients (13). Medication management is one of many areas of care given by (in)formal caregivers in the community setting (14-15). The role of caregivers is important as good medication management contributes to better health outcomes and reduced hospitalizations due to poor medication use (16). Given that informal caregivers often manage medications, it also logical to explore how caregivers view a personalized medication overview (MijnGiB) as a tool to support patient medication use.

The aim of this study was to gain insights into the opinions and experiences of patients and caregivers regarding MijnGiB after seeing the overview for the first time, and to assess patient experiences after having used MijnGiB for one month. Exploring their experiences might provide more insight into if and how tools like MijnGiB are helpful for patients for whom finding and interpreting reliable information about medications is more of a challenge. The research questions answered in this study are:

1. What are the general impressions patients and (in)formal caregivers have of MijnGiB when they first see it?
2. To what extent does the patients' judgment change after they have used MijnGiB for a month?
 - a. To what extent and how does this influence the patient's medication use?

This last question is only posed for patients, as they are the actual users of MijnGiB, while caregivers are more the ones who support patients in processing the information.

2 Methods

In this qualitative study we delved into what patients and (in)formal caregivers thought of MijnGiB after seeing it for the first time. Also, for patients we investigated how they experienced using MijnGiB after one month of use.

2.1 Participants

The patients and (in)formal caregivers were 18 years or older and understood the Dutch language. Patients were asked to take part in two interviews and (in)formal caregivers in one. Patients needed to meet the requirements that they use three or more medications and for (in)formal caregivers that their patients/family members use three or more medications. For both groups, they were not yet familiar (or have never received) MijnGiB.

Various recruitment activities took place to find suitable participants for the interviews. For the first few patients and all (in)formal caregivers, various pharmacies were contacted and different (social) media platforms were used to distribute recruitment flyers (i.e. Nivel's website, Twitter, LinkedIn, and Facebook). Also, non-profit organizations were contacted to reach out to patients and (in)formal care providers. For the remaining patients, a site visit to a pharmacy whereby the researcher could interview the patients face-to-face facilitated the recruiting process (due to the COVID-19 regulations this was only possible in a later stage of the research process).

2.2 Data collection

The interviews took place between February and August, 2021. All participants gave informed consent before starting the interviews. The interviews took about 10 to 30 minutes. The Medical Ethics Committee (METc) of the Vrije University Academic Medical Center (VUMC) approved the protocol (METC protocol number 2021.0031). The METc VUMC concluded that this study is not a clinical research with human subjects as meant in the Medical Research Involving Human Subjects Act (WMO).

2.2.1 Patients

Patients (n=10), who use three or more medications, were interviewed once. The first interview took place when the patients were not yet familiar with MijnGiB. During the first interview patients were asked about their medication use, comprehensibility of the use instruction on MijnGiB, and their views on MijnGiB. Also, we determined the health literacy of the patients by asking questions from the European Health Literacy Survey Questionnaire (HLS-EU-Q). This questionnaire included three parts of health literacy (health care, disease prevention and health promotion) (17). The health literacy score was calculated by coding the answers 'very easy' and 'fairly easy' as one and the answers 'fairly difficult' and 'very difficult' as zero. These answers were then added up, which gave a score between zero and sixteen. A score of zero to eight was considered to be low health literacy, between nine and twelve as sufficient health literacy, and a score of thirteen or more as high health literacy (18).

The second interview took place after the patients had been given the opportunity to use MijnGiB for a month. In the second round of interviews eight out of these ten patients were interviewed. During the second interview they were asked about their experiences with using MijnGiB. These questions included: how often they used MijnGiB, which information was useful/less useful, their trust in the information, their preference for type of use instruction information, and if they would recommend the use of MijnGiB to family/friends.

2.2.2 (In)formal caregivers

Ten caregivers were interviewed, of which seven informal and three formal caregivers. The interviewees were asked about their family member's/ client's medication use, the comprehensibility of the prescription medication label instructions presented on MijnGiB, and their views on MijnGiB.

2.3 Data analysis

The interviews took place online via Zoom or live in the pharmacy. Voice recordings were made with permission of the participant. After the interview, the recordings were transcribed verbatim. The collected data was analyzed anonymously. The transcripts were coded and analyzed. Two researchers analyzed the first six interviews independently from one and other, using deductive and inductive coding, to see if the same codes were used. Following, one researcher analyzed the rest of the transcripts. The deductive codes are derived from the topics used in the interview guide and the inductive codes from the interviews themselves.

3 Results

3.1 Patients' first encounter with MijnGiB

3.1.1 Patient characteristics

Six of the ten interviewees were 65 years of age or older (60%). The mean age of the sample was 64 years (range= 39-75) (Table 1). Most of the interviewees were males (80%), and had no paid job as they were retired (70%). All patients had a high health literacy score (score 13+) based on the HLS-EU-Q questions, though we have our doubts on the reliability of these scores as the HLS-EU-Q questions may not be the most suitable set of questions for in an interview. All patients had never seen or used MijnGiB previously.

Table 1 Patient characteristics

| Gender | N |
|--------|---|
| Male | 8 |
| Female | 2 |
| Age | |
| <40 | 1 |
| 40-64 | 3 |
| ≥65 | 6 |

3.1.2 Medication use

Most of the patients (80%) used three to six medications chronically, with the exception of two who used ten-plus medications. For most respondents, taking medication had become a routine, for example *"...I just do it every morning...[I've] been doing it for 20 years"* (male, 74). These respondents have their own way to remember their medication intake. Most use their own memory with help of a small reminder, such as setting out the medications on the kitchen table or a reminder in one's phone. A few respondents use other support systems such as multidose drug dispensing, or support from a partner. Almost all patients use their medications independently, with the exception of one respondent whose partner helps with their medication use. Respondents did not experience their daily medication use as a burden, as illustrated by this 63-year old female, *"I don't see it as a burden. It's just become a habit. It's just part of it."*

3.1.3 General Impressions of MijnGiB

The general impressions of the majority of the patients were that MijnGiB is clear and that information is well displayed. For some, the information confirms their actions, *"It's exactly what I've always done, so it confirms my actions"* (male, 47). Other respondents indicated that all essential information is displayed at a glance, *"it says what it is for and the time is very clear. Because you also see the packaging, you immediately know what it is all about"* (female, 63). For some respondents the medication overview was clear, but redundant for their own use. For example, as described by a

72-year-old patient, “[it’s] super clear, I mean if you are dependent on someone..., for example, the home care for your medicines...it seems really good to me, but for me it’s no” (female, 72).

3.1.4 Comprehension of use instruction on MijnGiB

Most respondents found all elements on MijnGiB overview to be comprehensible. Some respondents added that the information on the overview was comprehensible, but that they are very familiar with what they take and how much, and understanding the information is not necessarily based on the information presented on the medication overview, but based on their own experiences. As a respondent shared, “yes of course (it is clear)...I’ve known for years, I’m just saying” (male, 39). Another respondent indicated that in particular, the photos, quantities, and intake moments were clear. Lastly, for one of the interviewees the overview was less clear, and extra explanation was necessary to comprehend the overview:

“I think it’s a little clear what you’re explaining, the way you’re doing now, it’s a little easier for me to understand. Because if I have to look at that paper myself, I just don’t know where to look, you know?” (male, 39).

3.1.5 General Impressions of pictograms and photos on MijnGiB

Generally, the respondents were positive about the pictograms. The pictograms were viewed as positive, convenient, and clear. For example, as illustrated by a 47-year-old male, “I think it’s very clear. There are pictures, so you know exactly when to do what” (male, 47).

Most respondents found the photos clear and useful for recognition of the medication. For example, a 64-year-old male illustrated, “That you rightly have the impression of oh I have that. So, this box. It’s the same but it’s a different box. Then you recognize that a little easier.” Other respondents indicated that the photos are unnecessary. For one respondent, she does not see the medication box because her medications are organized in a multidose dispensing system (female, 72). Another respondent indicated, “I’m not that into that [the photos]. I’ll come get them [my medications] in a bag [from the pharmacy]. And I give them to my wife and my wife puts them all neatly in the cupboard” (male, 70).

There were mixed reactions about photos of the tablets/capsules on MijnGiB. For some the addition of these photos were necessary, for others not. For example, a 74-year-old male indicated “I think the pill size is an unnecessary addition.” Another respondent indicated, “I think it’s clear {the photos} and I think it’s necessary” (male, 47).

3.1.6 General impressions of type and amount of information on MijnGiB

Some of the respondents described the type and amount of information on MijnGiB to be the right quantity, well-displayed, and clear. A 47-year-old male indicated “It’s the same information I get from the pharmacy, but if you see it on a picture, it’s clearer” (male, 47). Another respondent, illustrated that she “likes that it says what it’s for. There are many people who don’t know that. They say they take something but don’t know what it’s for and I really like that you see that clearly here” (female, 63).

Other respondents indicated that it is (often) clear, but either a lot of information or paper. For example, a 70-year-old male patient indicated “the overview, yes it is nice. It depends on how many medications... If it becomes too much, it will no longer work for me” (male, 70). Another patient described that the overview contains a large quantity of information, but that it is still clear: “It does say a lot, but I think it’s okay with the size of the medicine and the boxes” (female, 63). Another patient who uses ten-plus medications indicated “It’s very clear, but it’s too much paper for me.”

(female, 72). Lastly, one patient indicated that there is lots of information displayed at once, *“It's a bit too much at once I just think”* (male, 39).

Regarding the type of information presented, most respondents indicated that there is nothing that they would add. There was one exception as one patient indicated that the side effects of the medication were missing. Also, the information that could be omitted from the overview, most of the respondents gave nothing as an answer. One patient suggested that the photos of the tablet/capsules could be omitted due to the frequent medication switches. She described the following: *“what could possibly [be taken away] are the pictures of the medications themselves. Medications sometimes change shape. The [medication name] used to be a bit rounder and now it's a bit more elongated. I have also worked with psychiatric patients and they would immediately become nervous if the medicines did not match the pictures.”*

3.1.7 General impressions regarding added value for own situation of MijnGiB

Respondents gave various reasons why MijnGiB could be of added value. For example, with medication switches, in case of uncertainty about medication use, or to check something quickly. A respondent elaborated on checking the facts quickly by explaining that *“[she] reads that information from the pharmacy once and [she doesn't] see it anymore. But if you would just keep this you can just quickly check it”* (female, 63).

Also a few respondents indicated that there is little to no added value for them. Some of their explanations were that their medication use has become a routine and the use of MijnGiB is not necessary. For example, a 64-year-old male explained *“Yes, it's nice, but if I didn't have it, I don't mind. I usually figure it out, you also get the advice here [at the pharmacy]... So actually, I've been taking it standard for years. I think that has already become a habit”* (male, 64). Another respondent illustrated that *“It doesn't help that much in that respect, because I already do what it says. Someone with more medicines will be able to benefit from it more”* (male, 47).

3.1.8 Trust in the information on MijnGiB

The majority of the respondents (70%) indicated that they have a high amount of trust in the information on MijnGiB. Most respondents had a high amount of trust because the overview was clear and it contained all necessary information. Also, some respondents explained that they trust the pharmacy staff and the information they receive from the pharmacy. For example, as a 64-year-old patient explained, *“Yes, I have every confidence in it. It's their job [the pharmacist/pharmacy technician]. I assume that. And this might give you a little more because you can put it next to it”* (male, 64). The remaining 30% either was neutral about the amount of trust they had in the information or they did not give an answer to this question.

3.1.9 Preferred way to receive use instruction information from the pharmacy

Amongst the respondents they had mixed views on what the preferred way is to receive use instruction information from the pharmacy. A few (four of the ten respondents) indicated that they only prefer instruction-label texts on the medication box. For example, as a respondent explained, *“What's on the boxes is enough. Those things are in the computer, they know what I'm coming to get and everything. I don't need any more information because I know what I'm taking”* (male, 39). Two of the respondents indicated that they would like the information on the medication box and MijnGiB overview. A respondent explained that she would only use a new MijnGiB if there were changes, *“It is very clear how and what”* (female, 63). Another respondent resonated the same idea, *“if the medication changes, I would like to get a new MijnGiB, if it hasn't changed, the label texts will suffice”* (male, 47). Other respondents (three out of the ten) indicated that the advice they receive

from the pharmacy is sufficient. For example, the multidose dispensing support and one single sheet overview with a medication list. Another respondent indicated that MijnGiB is sufficient, but if the amount of medication increases, then such overview would no longer work. Lastly, one of the respondents indicated that MijnGiB-only would be sufficient. This respondent explained that he believed that *“... you shouldn't get too much information either, because that also gets confusing. So yes, if I could get this [MijnGiB overview] it would be good”* (male, 64).

3.1.10 Likelihood of recommending MijnGiB to family and friends

There were mixed responses about the likelihood to recommend MijnGiB to family and friends. Some respondents (three out of ten), indicated that they are (very) likely to give a recommendation, most likely to other peers in the same age group. For example, as illustrated by a 68-year-old male, *“It is very clear to me. And especially people who... Yes, I'm already in an old age category. I like that this [MijnGiB overview] is available”* (male, 68). Another respondent explained that she found MijnGiB to be very clear, how often you have to take the medication, when, and what it is for. She indicated that this *“... makes it clear for people who don't know much about it and that they understand what they're using it for”* (female, 63).

Others (six out of the ten respondents) indicated that they were (very) unlikely to recommend MijnGiB to others. Respondents had various reasons for this, for example, that they found it too early to say, that they see no reason at this moment, that they do not speak about their medication use with family and friends, or that they do not know whether their family or friends used medications.

3.2 After one-month patient use

Of the eight respondents, three used MijnGiB in the past month and the rest did not. The respondents who used it indicated that they checked it once or twice, but that their medication use has become a routine (female, 63). Another respondent indicated that he checked it twice a week, to check when he had to take his medication (male, 47). The other respondent who used MijnGiB checked the overview because he did not have his glasses during the first interview. This respondent further explained that he *“certainly used it because there is an old product on it and a new product. [he] had to check it out okay. Yes, that's handy. You now know for sure that you are going to take the right medicine. So, I definitely used that”* (male, 64).

The respondents who did not use MijnGiB overview in the past month had various reasons why not. The main reason was that their medication use is a routine for them, *“...I get my medications like [I] always do... I just know”* (male, 39). Another respondent indicated that using a multidose drug dispensing and MijnGiB would be redundant and hence did not use the overview (female, 72). Another respondent had other personal circumstances in the past month and did not use the overview (male, 70).

3.2.1 General impressions added value of MijnGiB

Respondents indicated that MijnGiB can have added value in different situations (sometimes for themselves, and sometimes for others). Two respondents gave examples of how MijnGiB was of added value for them. One explained that it was clarifying, *“for example, for [name of the medicine], [a pictogram] for bright sun. I don't think I had read that before in the package insert. Then I thought oh that's enlightening. That kind of information is very good, that it is very concise. Because if you've been using it for a while, you really don't bother reading the package insert every time”* (female, 63).

Another respondent found that the intake moments on MijnGiB were clear, *“when I looked at it I could see when I had to take something, so that was handy to use”* (male, 47).

Other respondents indicated that MijnGiB could be of added value when in doubt or by medication switches. For example, a patient expressed that by medication switches MijnGiB could be handy, as she illustrated that *“... what I did notice is indeed all the pictures that are there of the medication box and the pills and such. Then I thought yes, it happens quite often that the box suddenly looks different or the pills are just a bit bigger or smaller or something”* (female, 63). This respondent further described that when people have doubts about their medication use, *“...then I think yes, people who doubt can really look back”* (female, 63).

Some respondents also indicated that they think MijnGiB can be of added value for others, not for those who routinely use medications, but for example for those dependent on a (in)formal caregiver or those prone to forgetting to take his or her medication. For example, a 39-year-old patient explained that *“I’ve been taking that for over six, seven years. I just know what I take, I know what it does to me and stuff. But other people maybe, just experience it differently. I do not know.”* Also, MijnGiB could be beneficial for older patients, according to some of the respondents. A 63-year-old female explained, *“I can imagine that when you’re older. That it’s all a bit difficult, or you don’t trust it all. It’s nice that you can control everything”* (female, 63). MijnGiB can also be of added value for patients that are dependent on others. A 74-year-old patient described that *“when you become dependent on others for care. Then such a quick overview of what should someone take per day and when, that can be helpful. Then they don’t have to go through all those medications boxes to see what’s on them.”* Lastly, a patient explained that *“we know roughly what we always take, ...but as soon as there are changes, yes, then it becomes difficult. My wife also has a whole mountain of medications and yes, she is also sometimes like yes, what do I have now”* (male, 64).

3.2.2 Trust in the information on MijnGiB

Respondents (n=4) had trust in the information on MijnGiB. For example, as described by a 60-year-old patient, *“I do have that confidence, what’s written on those papers. And for some people it will be people who, so to speak, have to take the medicines at different times. It will be practical anyway”* (male, 60). The other respondents indicated they would give a score of eight out of ten on the trust they have in the information on MijnGiB. Their explanations were that they think it’s a good overview (male, 47), a respondent has faith in that the truth is presented on the overview (female, 63), and that all the information is listed and is clear (male, 74). The remaining respondents did not answer the question as they did not use MijnGiB in the past month.

3.2.3 Preferred way to receive use instruction information from the pharmacy

The interviewees had split views on their preferred way to receive use instruction information from the pharmacy. Two respondents preferred MijnGiB-only because this overview list is sufficient (female, 63) and it is convenient (male, 64). Two respondents indicated that they would want both the prescription medication label text and MijnGiB because then they have all information needed (male, 47), or in the case there is a medication switch then you have the extra necessary information. This respondent explained that *“... [he] thinks the labels on [the medication box] are easy anyway, ... such an overview, if there are changes I find it very useful”* (male, 64). Moreover, two respondents desired the prescription medication label texts-only. For example, a 39-year-old patient stated *“no, no overview, just those [labels] is nice. [These labels are] enough for me. I’ve been taking [these medication for] so many years”* (male, 39). Another respondent described that he likes it how he has it now, *“Well, the way I have it now, I think it’s fine. Just that box... label. And yes, there is a*

description in the box of what is not good and what is good... the box already states when you should take it and how much and... so" (male, 60). The last two respondents did not state their preference.

3.2.4 Likely to recommend MijnGiB to family and friends

In the first interview three respondents indicated that they are (very) likely to recommend MijnGiB, six indicated that they are (very) unlikely to recommend MijnGiB, and one respondent did not give a response to this question. In the second interview, of the eight interviewed patients, five indicated that they are (very) likely to recommend MijnGiB to family and friends. These patients indicated that they would recommend it to people who may forget to take their medications, for people who use several medications, it could be helpful for others who support family or friends with their medication use. One patient who suggested that he would recommend MijnGiB to those who may forget to take their medication, both young and old. This respondent described how MijnGiB could help others in the following scenario:

"Yes, certainly... I have a grandson who has a certain illness and that, yes, he is sometimes a bit confused with taking medication. So, then I would say something like this: well, just read that piece of paper or that folder and check it out carefully, and then... But it's still a bit like "oh I forgot, that time" ... "that little thing [MijnGiB overview], you hang it in the kitchen, so to speak, or I don't know where you... in the shower. Some those people who can forget. If they read it through a few times, then of course they know what to do" (male, 60).

Another respondent illustrated that MijnGiB could be helpful when organizing the medications for another, as depicted in this quote:

"When they become dependent on others. I have a friend whose wife neatly fills his medicine box. It could work very well for that, then she can check every time whether she has put the right pills in the right compartments. I find it a very useful and complete overview" (male, 74).

One respondent indicated that they would be (very) unlikely to recommend MijnGiB to others, and the remaining two did not voice their opinion on this topic.

3.3 (In)formal caregivers' first encounter with MijnGiB

Half of the (in)formal caregivers were between 40 and 64 years old. The formal caregivers (n=7) were older (average 63 years old, min: 46 and max: 75), in contrary to the formal (n=3) caregivers (average age 39, min: 37 and max: 41).

Most of the interviewees were female. All interviewees were not yet familiar with MijnGiB because they had no heard of it or received it from the pharmacy before. The caregiver characteristics are shown in Table 2.

Table 2 (In)formal caregiver characteristics

| Gender | N |
|--------|---|
| Male | 3 |
| Female | 7 |
| Age | |
| <40 | 2 |
| 40-64 | 5 |

| Gender | N |
|----------------------------|---|
| ≥65 | 3 |
| Type of interviewee | |
| informal caregiver | 7 |
| Formal caregiver | 3 |

3.3.1 Support medication use of patient/client

The majority of the caregivers support patient/client medication use in some way. To help support patients with the medication use, all interviewees use an organization method to prepare the medications. For example, medication boxes, medication dispensers, medication lists, checklists, and a digital medication dispenser (called Medido) to help elderly remember when and which medications to take. Most informal caregivers help with the preparation of medications that are to be used by the client/patient. In these cases, the client/patient takes the medication on his/her own, but the caregivers for example organizes the medication in a medication dispenser, or in a bowl on the kitchen table. Another informal caregiver makes a medication list for their family member to indicate which medications ought to be taken. Other informal caregivers indicated that the formal care providers who took care of this caregiver's family member also took care of the medication use of the patient or that the patient themselves arranged their own medication use. The formal caregivers differed in their support for their patients' medication as they indicated that their support varied per patient and per day.

Caregivers stated that (almost) never anything comes in the way of the patient and the moment of taking their medication. A home care provider indicated that if something does come up causing the client to forget their medications on a frequent basis, then the patient can switch to a medication dispenser, called a Baxter roll. This formal caregiver further explained that if the medication dispenser is not sufficient, that the patient can then step over to medication dispensing by a caregiver.

Generally, caregivers considered supporting the medication use of a family member/client to be easy. It is (mostly) clear to all interviewees why and when the medications should be taken. For example, an informal caregiver indicated: *"Yes, almost everything is [clear], about 90%. I come across most of it in my work and the rest I have been given an explanation about"* (informal care giver, 46). For most, helping with the medication use of others has become a routine or it is part of their day-to-day work. For example, an informal caregiver illustrated that: *"It's very normal for me, because of my work. I don't even need a piece of paper anymore. I know by heart what and how much"* (informal caregiver, 46). In some cases, caregivers do find it challenging to support patients/clients with their medication. For instance, an informal caregiver indicated that it is sometimes difficult to remember that their family member needs to take his or her medication. This informal caregiver indicated that *"the fact that I always have to think about it is difficult for me. When I'm gone I have to make sure someone else picks it up"* (informal care giver, 69). Another reason why supporting clients with the medication use is not always easy is because the medication lists of the patient are not always correct. For instance, *"the list of medicines is often incorrect, which is difficult. The pharmacy is responsible for the list of medicines in connection with medication safety, but that is not quite right"* (formal care giver, 39).

3.3.2 Comprehension of use instruction on MijnGiB

The caregivers indicated MijnGiB to be clear and understandable. The interviewees were asked questions on prescription medication label instructions (i.e. intake frequency, intake amount, intake moment, condition for which a medicine is used). All interviewees gave the right answers for these interview questions.

3.3.3 General Impressions of MijnGiB

In most cases the caregivers are positive about MijnGiB. Most of the interviewees indicated that the medication overview is clear, as illustrated by this caregiver: *“It is very clear, it is very nice that it is there. It provides a lot of clarity and insight into the client's medication”* (formal caregiver, 37). Another informal caregiver specified that the key points on medication use are listed, *“The essentials are briefly mentioned here. Sometimes I don't even get the package insert. What is really essential is now being emphasized, which is very nice”* (informal caregiver and pediatric nurse, 46). Furthermore, an informal caregiver described the feeling they have with the new medication overview in an illustrative way, *“It actually says something more light-hearted about medication use...It has something funny about it somehow...that's a feeling I have about it. It doesn't feel that heavy, because medicines usually are. I think it's something positive, so to speak ...”* (informal caregiver, 58).

Despite that the majority of the interviewees find MijnGiB clear, one of the caregivers described that for them text is easier than the images presented on MijnGiB (informal caregiver, 75). Another interviewee indicated that some abbreviations presented on the MijnGiB are not completely clear. It was hard for this formal caregiver to tell if this was stated on the medication package (formal caregiver, 41). Also, an (in)formal caregiver indicated that in the pictures of the tablets/capsules, it is not clear and also confusing that one of the tablets is laying down and the other standing up whilst the patient only has to take one tablet (confusion two tablets in picture, and one tablet indicated for use) (informal caregiver, 73).

3.3.4 General Impressions of pictograms and photos on MijnGiB

Most of the caregivers indicated that the photos and the pictograms on MijnGiB are handy and clear. The pictograms were handy *“... for people who cannot read too well”* (informal care giver, 58). The same informal caregiver indicated that *“the pictograms also have a comical and clarifying aspect”* (informal care giver, 58).

One the caregivers illustrated that the photos of the medication packaging help with recognition of medication as *“[s/he] can imagine that if a patient doesn't have someone to put out the medication for him or her, it is useful to see which [medication] box needs to be used”* (informal caregiver, 46). It is important to keep in mind the switching of medications and the photos of the medication packaging. One interviewee explained that: *“[s/he] thinks it's good that it's there, because then you know which box it comes from. The only problem that does arise is when medication is put in a different box by the pharmacy at a given moment. Then it will of course not be recognized as such”* (informal caregiver, 63).

Interviewees were also asked about their impressions on the photos of the tablets/capsules. These photos were also perceived to be handy and clear. For example, an informal caregiver illustrated that *“some people also find it difficult to swallow. Then you have an image”* (informal caregiver, 58).

3.3.5 General impressions of type and amount of information on MijnGiB

For most of the respondents MijnGiB had a good amount of information presented in a clear manner. Others assumed that the essential information is presented on the medication overview. For example, the essential points are indicated and one can see the main points in one go (informal care giver, 46 and 58 years old). For the majority of the interviewees the amount of information was sufficient. Though, one of the caregivers indicated that MijnGiB may contain too much information, *“I think it’s a clear overview, but you have to read everything carefully...I think it’s not that bad, but someone who is very sensitive to stimuli, for example, might find it a lot, that’s possible”* (informal caregiver, 63). Another informal caregiver indicated that MijnGiB contains too much information.

In terms of which information could be left off MijnGiB, only one interviewee had a potential suggestion related to the dosage information. The interviewee indicated that the dosage information is listed twice given that there is a mark on the time of day the medication has to be taken (i.e. morning, afternoon, evening, before bed) and it stated that one tablet once a day has to be taken (informal care giver, 68). This feels like repetition. The others indicated that the information was sufficient or that they had no suggestions.

Interviewees were also asked which information they missed on MijnGiB. About one-third of the respondents indicated that there was information missing on MijnGiB. For example, a formal caregiver indicated the place on the body where an e.g. a cream or ointment should be applied and the amount that should be applied could be added. Another formal caregiver suggested that a place to sign off that the medication has been given. In addition, a checklist for the patient him/herself or for the informal caregiver once they have taken the medication. Moreover, information on whether someone has to take a certain medication only once a week is not easily depicted on MijnGiB. A caregiver indicated that it seems as if MijnGiB is made for someone who has to take the same medication every day. Another point that could be added according to an interviewee was the text: 'take with a glass of water' as part of the use instruction because older people already drink too little. Moreover, information on whether the medication use is a first-time occurrence, so that people can also see that it is a new or different medication. Lastly, information on the side effects are missing according to a few of the interviewees.

3.3.6 General impressions added value of MijnGiB

Most of the interviewees indicated that MijnGiB has added value for the medication use of the patient/client, for instance: *“I especially think the photos of the packaging and medicines add value. The combination with the pictures makes it very clear”* (formal caregiver, 41). On the contrary, one of the interviewees indicated that the information they currently receive is sufficient, *“what I had was good. Everything was already on the [prescription] labels”* (informal caregiver, 75).

Interviewees also indicated that MijnGiB can have added value for the caregivers themselves as well as the family members of the patients. For the informal caregiver themselves, an interviewee explained that it is clear and brings clarity, and in a glance you see what is needed for the patient (informal care giver, 58). A formal caregiver also illustrated the added value for family members of a patient in the following quote:

“Also, for family members when they come to them. When they come to them and see MijnGiB on the table or on the wall, they immediately know which medicines he/she is taking. Then they can ask whether they have already taken the medication and thus a forgotten intake can be prevented. It is certainly a good addition.” (formal caregiver, 37)

3.3.7 Trust in the information on MijnGiB

The interviewees rated their trust in the information presented on MijnGiB from a one to ten. The range score was between seven and ten. The informal caregiver who scored a seven indicated that *“It’s a bit confusing for me. It doesn’t have to be that extensive for me”* (informal caregiver, 75). The others who scored between an eight and ten indicated for example that the information is clear (formal caregiver, 37), the overview is innovative (informal caregiver, 58), and that MijnGiB is more attractive and visible to many people than just text (formal caregiver, 41).

3.3.8 Preferred way to receive use instruction information from the pharmacy

About half of the interviewees preferred to receive both MijnGiB and the prescription medication label texts. These caregivers explained that if there is a change in medication, a new overview is useful, otherwise the prescription medication label texts will be sufficient (formal caregiver, 41). Another informal caregiver indicated that the first time a patient receives his or her medication that it is important to have an extensive description of the prescription medication use instructions. For example, make use of the package insert out, but after that MijnGiB would be sufficient (informal caregiver, 58). Following, a few interviewees would only like to receive MijnGiB from the pharmacy. These interviewees gave the reasons 1) MijnGiB is sufficient as it is (formal caregiver, 39), 2). Everything is already on MijnGiB, then the prescription label texts are no longer necessary (informal caregiver, 69), and 3) one is more inclined to grab MijnGiB quicker than a list with only text (informal caregiver, 58). Lastly, one interviewee indicated that only prescription labels would be sufficient because *“the [prescription] label texts with the package leaflet are sufficient for me”* (informal caregiver, 75).

3.3.9 Likelihood to recommend MijnGiB to family and friends

Most of the interviewees would be (very) likely to recommend MijnGiB to family and friends (Table 3).

Table 3 Likely to recommend MijnGiB to family and friends

| Would recommend | |
|---|----------------------------------|
| <i>“I would definitely recommend it to someone who is on a lot of medication. These are often the elderly or people who are chronically ill. These people are often less strong in their memory, so this would be perfect.”</i> | Formal care provider, 37yrs old |
| <i>“Because it really is a nice and clear overview. If you follow this, you will take the medication properly and you will know what to watch out for.”</i> | Informal caregiver, 46yrs old |
| <i>“I think it is especially useful for people who take medication several times a day.”</i> | Informal caregiver, 69 years old |
| Would not recommend | |
| <i>“I wouldn’t recommend it, but just recommend the [prescription] labels with the package leaflet because I think that’s enough.”</i> | Informal caregiver, 75 years old |

3.3.10 Points for consideration regarding MijnGiB

Lastly, during the interviews with caregivers, a few points arose that may need further attention. The first point being medication switches and how to go about that on MijnGiB. An informal caregiver explained that if the medication changes, it also means that the paper has to change. Another point is the eco-friendliness of the paper print outs of MijnGiB. As described by an informal caregiver, if MijnGiB is handed out each time with the medications the patient receives each time, given that medication changes also occur often, this is not necessarily environmentally friendly given the load of paperwork (informal caregiver, 63). Lastly, a formal caregiver indicated the importance that MijnGiB is free for patients.

“But it shouldn't cost money, because that's very important to many people, just like the costs for a first issue [of a medication]. It is better to get such a piece of paper than those costs. Sometimes it is very busy in the pharmacy and it is not even explained properly” (formal caregiver, 37).

3.3.11 Further suggestions for development on MijnGiB

One suggestion was the digitalization of MijnGiB. For example, on a digital version a pop-up could be added so the patient/caregiver can access the side effects. Also, a digital copy sent to one's mail could be beneficial for caregivers. A caregiver depicted a case where if the caregiver would be out of the running that you could then mail or send a text message with MijnGiB to someone else to take over their tasks (informal caregiver, 58). Moreover, the same informal caregiver highlighted the benefit of having a pocket size version of MijnGiB of the family member who they support with medication use.

Also, suggestions were made for MijnGiB and other target groups. For example, for people who cannot see that well, it is important that the icons are made bigger (informal caregiver, 69). Also, potentially for those who are deaf, sometimes this target group can read comprehensively, but text should not be too difficult. Pictures on MijnGiB could help this target group with understanding use instruction information (formal caregiver, 41).

4 Discussion and conclusion

In this study we answered the following questions:

1. What are the general impressions patients and (in)formal caregivers have of MijnGiB when they first see it?
2. To what extent does the patients' judgment change after they have used MijnGiB for a month?
 - a. To what extent and how does this influence the patient's medication use?

4.1 General impressions

In general, patients were positive about MijnGiB, though rarely used MijnGiB as they already used medications on a routine-basis. For these patients, the information on MijnGiB was (mostly) clear and comprehensible. For some, the information on MijnGiB is at times overwhelming (i.e. the quantity of the information). Most of the patients indicated that the pictograms and photos of the medication box and tablets/capsules are helpful in recognizing their medication, while some found them to be unnecessary. The majority of the patients suggested that MijnGiB could be of added value in case of medication changes or uncertainties about their medication use. After a month, only a few patients used MijnGiB. Those who used the medication overview indicated they used it to check their medication use (i.e. intake moment, medication change), though the majority indicated that their medication use is a routine and checking MijnGiB was not needed.

Generally, caregivers were also positive about MijnGiB. All caregivers indicated that the information on MijnGiB is comprehensible. The majority found the pictures and pictograms to be handy and help provide overview. Caregivers also suggested MijnGiB can be of added value when there are medication changes, but also for other caregivers such family and friends, aside from themselves, who may support the patient in their medication use.

4.2 Medication changes

Both patients and caregivers indicated that MijnGiB can be of added value in the case of medication switches or changes in medication use. Medication switches and medication changes are common in the Netherlands, specifically amongst patients with polypharmacy. According to research by 14 patient organizations, a million patients experience a non-medical medication switch once or more every year (19). In that study, the majority of respondents found the switch to be a problem, 40% experienced side effects from the new medications, 37% felt insecure about the new medication and 34% felt as if their health worsened after the medication switch. In the case of frequently changing medications, an overview with the medications a patient uses may be helpful. Remembering to take one's medication (and which medications) is a vital tool in aiding adherence to conventional treatment (20). Hereby, MijnGiB can support patients in keeping overview of their medication use. MijnGiB can be positive for adherence as it can allow for more routinization for patients taking medications.

4.3 Patient journey in medication use

The interviewed patients use medications on a routine-basis, and often for several years now. We chose patients who use three or more medications because we initially thought that a personalized medication overview with all their prescribed medications listed would help create overview of their medication use. The majority take their medication independently, have different ways of organizing their medication use, and do not experience their medication use as a burden. MijnGiB may be less tailored for this group of patients. Though, MijnGiB may be of interest specifically for certain patient groups who are in a different phase in their medication use. The ABC-taxonomy of Vrijens et al. (2012) distinguishes between different phases in medication use (21). The initiation is when the patient starts taking the medicine. The implementation phase is the period during which the patient uses the medications as agreed with the prescriber. Discontinuation is when the patient stops taking the medicine, whether or not in consultation with the prescriber. At each stage, the need for information may be different. Information that someone needs at the start of their treatment is different than when the medication has been used for a several years on a routine basis. At the start of a therapy, people may need more explanation about the effect and side effects of the medicine and also how they should use the medicine. For this specific group of patients, MijnGiB could be of added value.

4.4 Support in patient medication use

Medication adherence is complex, whereby not only the self-management of the patient plays a role, but also support of caregivers and healthcare professionals. The pharmacy team has an important role in the promotion of patient self-management when it comes to medication use (22). They are generally the last health care professional patients encounter before taking their prescribed medications (23). During this encounter between the pharmacy staff and patient, there is a window of opportunity to inform and counsel patients before, but also while they take their prescribed medications (24, 25). Providing clear and comprehensible medication information is key. Pharmacists can therefore help detect whether MijnGiB may be suitable for the patient at the counter (i.e. polypharmacy patients, patients who are in an early stage of their medication use journey, patients who may find it difficult to keep overview of their medication use, like those patients who often encounter medication switches). Moreover, MijnGiB could also be a good basis for explaining how to take the medication and then the pharmacy staff can use the teach-back method to check the message has been received well by the patient. This method entails that the pharmacy staff asks the patient to repeat in their own words what the pharmacy staff has just discussed. After this the pharmacy staff can adjust the explanation if necessary. In this case, the use of MijnGiB can be more imbedded in healthcare and ensure better recall through repetition and combination of information.

Moreover, caregivers have a signaling function in the medication use of patients. Long-term care continues to shift from institutional care to home and community options whereby family members and (in)formal caregivers play a role in the increasingly complex care of patients (13). The role of caregivers is important as good medication management contributes to better health outcomes and reduced hospitalizations due to poor medication use (16). Given that informal caregivers often manage medications, they have a vital role in detecting how the medication use of the patient is. In these cases where the patient finds it difficult to keep overview of their medication use, MijnGiB may be a helpful tool for such patients and for caregivers to keep overview.

4.5 Implications for practice and research

- Patients with polypharmacy and in the beginning of their medication use journey can benefit from the use of MijnGiB.
- MijnGiB can be helpful in keeping overview for patients experiencing frequent medication switches and changes.
- MijnGiB can be positive for adherence as it can allow for more routinization for patients, who find it difficult to keep overview, in taking their medications.
- MijnGiB may be less useful for patients who already use their medications on a routine-basis for several years.
- Given that informal caregivers often manage medications, they have a vital role in detecting how the medication use of the patient is. In these cases where the patient finds it difficult to keep overview of their medication use, MijnGiB may be a helpful tool for such patients and for their caregivers in supporting their patients to keep overview.
- Pharmacists can help detect whether a MijnGiB overview may be suitable for the patient at the counter (i.e. polypharmacy patients, patients who are in an early stage of their medication use journey, patients who may find it difficult to keep overview of their medication use, like those patients who often encounter medication switches). This should be further investigated.
- MijnGiB could also be a good basis for the pharmacy staff to explain how to take the medication, whereby the pharmacy staff can use the teach-back method to check whether the message has been received well by the patient. This should be further investigated.

4.5.1 Strengths and limitations

A strength of this study is that we interviewed both patients and caregivers. Caregivers support patients in their medication use, and hence understanding their views on MijnGiB is also important rather than solely from the patient perspective. Another strength is that we interviewed patients twice, when they first see MijnGiB and after one-month use. These two interviews provide insights into whether and how MijnGiB is useful for (which type of) patients. Lastly, the interviews were held after the experiment (Part A of this study), which helped provide more in-depth insights in the views on MijnGiB and the comprehensibility of the medication information.

A limitation of this study is that we only interviewed patients who use medications on a routine basis and for several years. Further research among new medication users, or people who receive a new medication in addition to existing medications is key to understand the added value of MijnGiB for these patient groups. Another limiting factor is that we cannot conclude on the added value of MijnGiB for people with a low health literacy. All patients had a high health literacy score (score 13+) based on the HLS-EU-Q questions, though we have our doubts on the reliability of these scores as the HLS-EU-Q questions may not be the most suitable set of questions for in a spoken interview (instead of filling in the questions on paper).

4.5.2 Conclusion

Patients and caregivers are generally positive about MijnGiB, as according to most it contains comprehensible and clear information. Although not everyone would use MijnGiB, there is a group of medication users who do use MijnGiB and appreciate it. Those who do not use MijnGiB do however see the usefulness in certain situations or for others types of patients.

MijnGiB can support patients who experience medication changes and those with polypharmacy especially at an early stage of their medication use journey when patients still have to figure out how

to use the new medication and include it in their daily routines. Further research is needed to understand what new medication users think of MijnGiB. The pharmacy has an important role in giving suitable and tailored information to patients, and MijnGiB can be one of the tools they use for that. Caregivers also have a key role in supporting patients with the medication use, and MijnGiB can be useful in keeping overview of the medication use of the patient.

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