# Web-based Lifestyle Management for Chronic Kidney Disease Patients in a Clinical Setting

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***Abstract*—Maintaining a proper lifestyle is important for chronic kidney disease patients. This study investigates whether an online lifestyle diary supplementary to the support received in the outpatient clinic can help patients to get to such a lifestyle. A total of 33 participants expressed their willingness to participate in the study. However, 11 of them did not start actually. The remaining 22 participants used an online lifestyle diary. They received limited support regarding practical issues and feedback on lifestyle issues only when they asked explicitly. Questionnaires were used to determine the change in self-efficacy and self-management with regard to lifestyle after four months. Only five participants used the website successfully. They had already developed a good self-efficacy and self-management. A disappointingly large group hardly used the website. The effectiveness of using the website regarding self-efficacy and self-management was therefore limited in this particular situation. Insights of the outpatient clinic's caregivers and information from the participants partly clarify the factors involved in lifestyle management and coaching. Motivation of the participant appears to be an important factor as well as setting realistic goals. If a patient were to receive feedback on lifestyle issues regularly while working with the website, more satisfactory results might be obtained. Finally, the participant's (computer) skills and practical support played an important role. Taking these factors into account, the already comprehensive task of lifestyle coaching would be extended with specific new tasks, requiring the necessary skills and motivation of the caregiver.**

***Keywords-chronic kidney disease; healthy lifestyle; online lifestyle diary; self-efficay; self-management; intervention.***

## I. INTRODUCTION

It has been estimated that among adults the prevalence of chronic renal failure, varying from mild renal insufficiency to end-stage renal disease, is between ten and eleven percent [1]. Since age plays an important role in the development of renal insufficiency, with an aging population the prevalence of chronic renal disease will only increase.

It has been recognized that for many patients maintaining a proper lifestyle helps to reduce the deterioration of the renal function [2, 3]. Besides taking the prescribed medication, regular exercise, smoking cessation and maintaining a healthy weight, a specific kidney failure diet is an important part of the treatment plan [4]. The recommended diet may change over time if the kidney disease deteriorates.

The Isala klinieken in Zwolle is one of the Dutch hospitals with an outpatient clinic for chronic kidney disease (CKD) patients. Often these patients need to adapt their lifestyle. A multidisciplinary team which consists of nephrologists, dieticians and nurse practitioners supports the patient in achieving the necessary behavioural. Interventions made by the team aim at increasing the self-efficacy and the self-management of the patient. For the caregivers in Zwolle motivational interviewing [5] is the preferred conversation style when they talk with patients about lifestyle.

Obviously the treatment varies from patient to patient, as does the number of visits to the clinic. Typically a patient will have two conversations per year with a nurse practitioner about issues concerning lifestyle, self-efficacy and self-management beside treatment by a nephrologist and advice from a dietician. The nurse practitioners found the time between two such conversations too long for their patients. Opportunities to support them better between visits in the outpatient clinic were therefore investigated. This led to the question whether a web-based tool, supplementary to the support from the outpatient clinic, could help patients to maintain a proper lifestyle [6, 7].

The results of a randomized controlled trial by Chen et al. [8] indicate that a standardized self-management support programme may play a significant role in reducing CKD progression and morbidity of late-stage CKD patients. Jansen et al. present an intervention programme for patients with end-stage renal disease and their partners [9]. Their findings show that an approach in which cognitive, emotional, behavioural, and contextual aspects are integrated is promising.

However, a study by Elzen et al. [10] did not yield any evidence for the effectiveness of the well-known Chronic Disease Self-Management Program (CDSMP) on self-efficacy, self-management behaviour or health status of older patients in the Netherlands. The authors presume a ceiling effect, pointing out that in the Netherlands chronically ill patients do not usually only see a physician, but also a specialized nurse who gives them a lot of information about various aspects of self-management. Blanson Henkemans et al. recognize that self-management has become common practice [11]. They advocate a longitudinal empirical study

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to investigate whether self-management will lead to labour savings.

Self-management programmes may be complemented by web-base lifestyle tools. Wyatt et al. evaluated the effectiveness of an Internet-based 12-week programme in supporting weight loss [12]. They found that this programme could, among others, successfully produce meaningful weight loss. Dilorio et al. report the results of a research study evaluating a web-based epilepsy self-management intervention [13]. The study findings show that this programme can be an effective means to encourage self-management. Araújo et al. compared the feasibility and clinical outcomes of a standard paper-based asthma self-management strategy with web-based strategies [14]. They concluded that web-based management was feasible, safe, and preferred by patients. They found that short-term outcomes were at least as good. Bromberg et al. studied a web-based intervention to improve migraine coping and self-management [15]. They concluded that this intervention may be a useful behavioural adjunct to a comprehensive medical approach to managing migraine. Blanson Henkemans et al. enhanced an online lifestyle diary with a persuasive computer assistant (an animated iCat) [16]. They concluded that this approach is likely to support motivated overweight people and individuals with lifestyle-related diseases to get a better insight into their self-management and adhere to it.

However, some studies report poorer results. Kerr et al. studied web-based interventions for heart disease self-management [17]. This study showed that the intervention did not result in a large number or all types of patients with coronary heart disease using the intervention for self-management support. Verheijden et al. investigated rates and determinants of repeat participation in a web-based health behaviour change programme [18]. They found that behavioural intervention programmes may reach those who need them the least. Kelders et al. investigated the users and effect of a web-based intervention aimed at healthy dietary and physical activity behaviour [19]. They found that respondents did not use the application as intended and that users were healthier and more knowledgeable about healthy behaviour than non-users. Nijland et al. explored the factors that influence the initial and long-term use of a web-based application for supporting the self-care of patients with type 2 diabetes [20]. This study also mentions a ceiling effect. Moreover, usage of the application was hindered by low enrolment and increasing non-usage.

None of these studies deals with web-based lifestyle management for chronic kidney disease patients. The present paper therefore discusses the introduction of a web-based lifestyle diary supplementary to the care CKD patients receive in Isala's outpatient clinic. A pilot was carried out to determine the effectiveness with regard to self-efficacy and self-management of using an online lifestyle diary.

The paper is structured as follows. Section II discusses the preparatory steps taken before the pilot started, followed by a description of the applied method in Section III. Section IV gives an overview of the results of the pilot followed by a discussion in Section V. Section VI concludes the paper.

## II. PREPARATORY STEPS

Based on the results of interviews conducted with caregivers at Isala's outpatient clinic, an Internet search was carried out in order to select a lifestyle management website for CKD patients. Eleven candidate software tools were identified. Of these candidates dieetinzicht.nl [16] was considered the most promising application.

To verify whether the selected website was suitable for supporting lifestyle management for CKD patients a user experiment was conducted involving six participants who all had undergone a successful kidney transplant. After a week they completed a questionnaire in which their experiences were recorded. Further information was collected in a focus-group meeting.

The participants held the opinion that the website they had used should not be seen as a replacement of the contact with caregivers but that the website would contribute to the lifestyle management of patients with CKD. Moreover, they indicated that patients should be sufficiently skilled in using a computer.

June 2011 Bonstato B.V. launched mijnnierinzicht.nl, a new website based on dieetinzicht.nl [21]. This new website has been developed with support of the Dutch Kidney Foundation ("de Nierstichting") and augmented the original website, among other things, with a communication module and the possibility to record data about daily exercise as well as smoking habits. The website mijnnierinzicht.nl contained all functionality required for the pilot. Moreover, it offers extensive support for maintaining a proper diet. By accurately entering data about consumed meals in a diary, comprehensive information can be obtained about nutrition components such as minerals and vitamins in the CKD patient's diet. For this purpose mijnnierinzicht.nl contains a database with information about a large number of products. Most of the aforementioned studies did not report such an elaborate functionality.

To check the materials developed for the pilot, such as a Quick Start Guide, and the intended procedure, a pre-pilot was conducted. For this pre-pilot seven patients were invited who had dialysis. They used the website for one to two weeks. Five participants completed the pre-pilot, the two others stopped due to personal circumstances. The pre-pilot only led to minor adjustments in the tested materials. One of the participants was particularly confident: *"This can hardly go wrong, even for the elderly and people who are not used to working with a computer the manual is very clear."* Some participants were positive about mijnnierinzicht.nl ("*a beautiful site which certainly has added value*"), although another participant warns that the site is too time-consuming in proportion to the benefits.

## III. METHOD

Participants in the pilot were selected from Isala's outpatient clinic for patients with chronic renal insufficiency. None of them had dialysis. Moreover, they should be able to use a web browser and e-mail and speak Dutch. Depression or cognitive complaints could be a reason for exclusion. Patients who were considered to be potentially successful

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users of the website were invited for the pilot in a telephone call some days before their next visit to the clinic. If they were willing to participate, they were sent a two-page sheet containing information about the pilot.

At the next visit to the clinic the participants filled in an informed consent as well as the first of two questionnaires. This questionnaire contained seven questions dealing with self-efficacy related to lifestyle. Five questions dealing with self-management completed this questionnaire.

The participants also received a Quick Start Guide, both in print and on a USB-stick. This 33-page guide informed them how to enter data with respect to diet, activities (sport, leisure) and smoking habits. It also showed how users could get insight into their lifestyle, using the various tables and graphs of mijnnierinzicht.nl. Moreover, a chapter dealing with the communication module was added. The participants were free to decide how often and when they wanted to use the website and for what purposes.

The participants were asked to use the website for four months. After a week they received an e-mail asking them whether they had actually started. Help was offered if needed. During the pilot, participants were invited to ask for assistance or to ask for feedback through the communication module of the website. Obviously, if they contacted the clinic in the usual way such as by e-mail or telephone, they were answered equally. Each month the participants received an e-mail in which they were invited to attend an informal consultation hour where they could also receive help if they encountered any practical difficulties in working with the website. In this e-mail participants were asked to report how many times they had used the website in the past month. The e-mail also contained a newsletter informing the participants about the progress of the project. Each newsletter contained an interview with somebody who was involved in the project.

Two types of support should be distinguished: help with practical issues such as creating an account for the website and support regarding lifestyle. As all sorts of tasks are done nowadays using the Internet, such as buying books and completing tax forms, it was expected that most participants would be able to use the online diary independently with the help of the Quick Start Guide. Only when the patient took the initiative to contact the caregiver, for instance via the communication module of the website, lifestyle-related advice was given. This study looked into the effects of using the website separate from the usual treatment on self-efficacy, self-management and lifestyle.

After a period of four months the second of two questionnaires was sent to the participants. This second questionnaire repeated the questions of the first so that changes in self-efficacy and self management could be determined. Moreover, questions were added asking whether the website had helped to achieve a proper diet, a healthy weight, sufficient exercise and smoking cessation. It was also asked whether using the website was time-consuming and difficult to use. Participants also reported about the added value of the website and it's communication module to the visits at the clinic. A question was added asking about the frequency of use of the website. The second questionnaire allowed the participants to add explanations to their answers.

If the second questionnaire was not received in due time, the participant was contacted by telephone, or e-mail or reminded orally at their next visit in the clinic. In order not to damage the trust between clinic staff and patients, participants had to be treated with gentle insistence.

Finally, the researchers discussed the results with the participating caregivers of the outpatient clinic in a focus group meeting.

## IV. RESULTS

A total of 33 participants expressed their willingness to participate in the pilot. However, eleven of them did not actually start. They did not hand in an informed consent nor the first questionnaire (Group I). From seventeen participants an informed consent and a first questionnaire were received, but this group hardly used the website (Group II). Five participants used the website often enough to be meaningful for them, as described below (Group III). Table I summarizes the main results of the three groups. Age only seems to play a role in actually starting. The numbers for self-efficacy and self-management are rated on a scale from 1 to 5, with 5 representing a high self-efficacy and high self-management. The figures in Table I should be treated with caution because of the small number of participants. The table suggests that the participants in Group III had already developed a better self-efficacy and self-management than the members of Group II. No significant differences were found between the first and the second questionnaire with respect to self-efficacy. On average, only self-management regarding nutrition changed: the five participants on average scored 0.8 points higher. Next the response rates of the e-mails sent to the participants are included in the table. Again, Group III shows better results. Finally, the table shows the reasons why the participants in Group I and II did not use the website successfully. They informed the research team about these reasons responding to the monthly e-mails or through other contacts such as visits to the clinic.

TABLE I. MAIN RESULTS OF THE PILOT

| Group | I | II | III |
|---|---|---|---|
| group size | 11 | 17 | 5 |
| male / female | 8/3 | 13/4 | 4/1 |
| age (av.) | 59.8 | 55.2 | 55.6 |
| number of smokers | N.A. | 2 | 0 |
| self-efficacy (av.) before pilot | N.A. | 3.7 | 4.5 |
| self-efficacy (av.) after pilot | N.A. | N.A. | 4.4 |
| self-management (av.) before pilot | N.A. | 3.4 | 4.2 |
| self-management (av.) after pilot | N.A. | N.A. | 4.4 |
| response month 1 | N.A. | 41 % | 60 % |
| response month 2 | N.A. | 24 % | 100 % |
| response month 3 | N.A. | 29 % | 60 % |
| response month 4 | N.A. | 35 % | 80 % |
| too busy or lack of motivation | 3 | 2 | N.A. |
| technical problems | 1 | 3 | N.A. |
| lack of (computer) skills | 4 | 8 | N.A. |
| unknown or other reasons | 3 | 4 | N.A. |

The technical problems mentioned in the table include not having Internet at home. Among the reasons referred to

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in the bottom row of the table there was a case of severe illness. To mention another example, one participant refused to create an account because of bad experiences with other organizations. In more than half of the cases participants stopped due to technical problems or lack of skills.

One of the five participants in Group III had developed his own Excel application to store information for lifestyle management concentrating on sodium, potassium and protein. He has been using it for a long time. He entered data in mijnnierinzicht.nl for 25 consecutive days and after that with decreasing intensity until he found confirmation from the website that his lifestyle was indeed healthy. He felt that the website might be difficult to use for elderly patients but considered the website very useful for patients who had just learned that they suffered from renal insufficiency.

A second participant used mijnnierinzicht.nl to learn about the components in his nutrition, for which he considered the website very valuable. Once he had detected a recurrent pattern he stopped with the intention to use the website again if necessary. At some point the laboratory results of this participant showed a high sodium level in his urine. The website helped to find out that this was caused by the medicines he used and not his diet.

A third participant of these five used the website to get to a proper diet and a healthy weight. Once he had reached his goals he decided to use the website less intensively. A fourth participant benefitted from the website to reach a healthy weight and a sensible diet with respect to potassium and sodium. The last of five participants used the website to get to a proper diet.

All five participants reported that they had experienced no difficulty using the website. Four of them felt that it took little time to enter the necessary data while a fifth participant answered neutral. It should be noted that the participants filled in the second questionnaire after having spent time using the website. A participant who reported that entering the data took little time mentioned in an e-mail a few weeks after he had started that working with the website was time-consuming.

With respect to the question whether the website was useful in addition to the conversation in the clinic about lifestyle the picture was unclear. The same goes for the question whether the communication module of the website was helpful in maintaining a healthy lifestyle. Opinions among the participants were divided with respect to both questions.

During the focus-group meeting the caregivers recognized the potential value of the website for their patients. Moreover, they realized that they could gain more detailed information faster. The caregivers discerned a number of factors which may influence the successful use of an online lifestyle diary. Apart from the patient's motivation and skills and the question whether the patient can spend enough time when being introduced to the website is of importance. If a patient is just starting to realize the consequences of his or her disease, it may be sensible to postpone the use of the website for some time. Considering the high number of patients who hardly used the website, the caregivers discussed the possibility to integrate the online lifestyle diary in the existing coaching process. Although they expected an improvement of care if feedback was given more actively, it remained unclear whether this would lead to more efficiency.

## V. DISCUSSION

The aim of this study was to determine the effectiveness with regard to self-efficacy and self-management of using an online lifestyle diary. CKD patients were asked to use the diary supplementary to the care they received from the outpatient clinic. Participants in the study worked with this online diary independently, which meant that they did not receive active coaching aimed at goal setting when using the website, nor did they receive any guidelines regarding the duration or frequency of use of the online diary. The help offered was mainly concerned with practical use of the website. Regarding lifestyle issues the participants were not supported actively while working with the website. However, they were invited to ask questions about their lifestyle, preferably using the communication module of the online diary.

Apparently, for a minority of the participants this was sufficient. In view of the results from Table I it is not surprising that an overall improvement could hardly be observed, comparable to the ceiling effect mentioned before [10, 20], with an exception for self-management regarding nutrition. These participants were motivated to change their lifestyle if necessary and were able to set realistic goals. The higher response rate of the monthly e-mails also illustrates the motivation of this group.

Despite their willingness to participate in the present study a large majority of the participants did not use the website successfully for reasons mentioned in Table I. Such results were disappointing. Some of the aforementioned studies have reported comparable results [17-20].

Insights of the caregivers, the positive results observed and the reasons why participants hardly used the website help to understand web-based lifestyle management better. It should be noted that the reasons for the poor results are multifactorial and that the findings of the present study do not clarify the relations between the various factors involved. It is possible, however, to mention a number of important factors.

### *A. Motivation*

Caregivers noticed that patients may wish to carry on with their life and be reluctant to spend time on detailed lifestyle management tasks, despite their chronic disease. Not all patients who want to take up such tasks may find the idea of working with a computer very attractive. The routine of regularly entering data into the online diary over a prolonged period of time requires concentration and time. When advising a patient to use an online lifestyle diary, one should take into account the patient's stage of change discerned in motivational interviewing and verify whether the patient is sufficiently motivated to change their lifestyle and use the website, taking into account socially desirable responses. Can he or she find the discipline to use the website long enough? Internal and external motivation

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factors should be discerned. Conversations with participants suggest that in the present study some of them may have been motivated extrinsically because they were prepared to help researchers when kindly asked. Obviously this motivation differs from an intrinsic motivation to improve one's their lifestyle.

### *B. Realistic goals*

Participants using the website successfully did so for a specific purpose and during a sufficiently long but limited period of time. They tended to use the website when special events occurred or when they felt the need to obtain conformation about their lifestyle. This shows, in accordance with the findings of behavioural psychology [22], the importance of setting specific and attainable goals. If the caregiver should, contrary to the approach taken in this study, choose to coach patients in setting goals for working with the website, it might be expected that patients gain more from it. In such an integrated approach (i.e. integration of using the online lifestyle diary in the existing coaching process) the caregiver will discuss goals with the patient, taking into account, among other things, the illness perception of the patient and the necessary change in lifestyle. Moreover, the caregiver will advise about the period of time and frequency of using the diary.

### *C. Feedback and coaching*

A further step in integrating the usual coaching and the online lifestyle diary would be taken if the caregiver should look actively into the information entered by the patient in order to give feedback. It may be expected that patients will be encouraged to improve their lifestyle with the help of the website if they receive feedback regularly: Nijland et al. remark that in their study personalized feedback appeared to be one of the most promising features for long-term usage of the application [20]. Initially this feedback can be given more often. Later on, as the patient is sufficiently empowered, the time between two contacts may be longer. To avoid surprises it should be agreed beforehand when messages will be received. Depending on the nature of the feedback a response may be given in writing, over the telephone or face to face.

### *D. Skills and practical support*

Obviously, for web-based lifestyle management patients should have easy access to a computer and the Internet. Moreover, the patient must be sufficiently skilled in using a computer. Even with an increasing number of people who use a computer regularly this remains an issue as entering detailed information in an online diary requires skills that differ from ordinary tasks. Help with technical problems and training must be separated clearly from feedback on lifestyle topics. For example, one of the participants in this study faced problems creating an account because he was not aware that a username should not contain a space. Preferably, such practical problems should not be dealt with by caregivers (although they did so in a number of cases) but, for instance, by a helpdesk.

Summarizing, it is clear that web-based lifestyle management can be a complicated and elaborate task for CKD patients. Advising when and how to use the website caregivers should weigh each patient's unique situation. The present study shows, however, that it can be difficult to assess a patient's skills and motivation properly, demonstrating the need for improved assessment tools and techniques.

### *E. Further considerations*

A changed approach to patients who work with the website as described above may also affect the daily work of caregivers. Apart from logistic matters such as reserving time slots to give patients feedback via the communication module of the website, the necessary infrastructure must be realized. For instance, integration of the data for the online diary tool with the patient's Electronic Health Record is expedient. It remains unclear whether the care improved through the website will be more time-consuming or not.

Some of the factors mentioned above can be found also in the usual coaching. The importance of setting realistic goals, for instance, is widely accepted. However, web-based lifestyle management adds new aspects to the caregiver's already extensive task of lifestyle coaching. Apart from assessing the patient's skills and motivation for online lifestyle management, new opportunities and challenges emerge when care is given through online feedback. What applies to patients equally applies to caregivers: they should be sufficiently motivated for online lifestyle coaching and may need to acquire new skills for that.

Moreover, in order to be successful web-based lifestyle management needs to be facilitated sufficiently. The user-friendliness of the online diary should be improved. To mention two examples, navigation must be intuitive and the database for nutrition products should be as complete as possible and more easily accessible. Finally, the website used in this study can be used without cost until 2016. However, given the tendency in the Netherlands to implement e-health only as a substitution of the usual care [23] an extensive financial analysis is necessary for online lifestyle coaching.

## VI. CONCLUSION AND FURTHER RESEARCH

In this small-scale qualitative study an online lifestyle diary was introduced while participants were helped mainly with practical issues only. With this approach only a small group of users used the online diary successfully. It follows that the effectiveness of using the website with regard to self-efficacy and self-management was limited in this particular situation. Web-based lifestyle management appears to be a complicated and elaborate task for patients, requiring motivation and skills. Lifestyle coaching with an online diary, integrating the website into usual care, likewise requires motivation and skills.

To reach the full potential of web-based lifestyle management and coaching a number of issues must be addressed. The concept of online lifestyle coaching needs to be developed further exploring questions such as how a caregiver can appropriately assess a patient's skills and motivation, how to estimate which support will be necessary

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and how the intensity of online lifestyle coaching should change over time. Further development of web-based lifestyle management and coaching needs to be rooted in behavioural theory, applying an adequate psychological model, and needs to clarify the relations between the various factors involved. Finally, technology can still be improved, including usability of the website.

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