NutriDia-Nutritional Decision Support between Cancer Patients at Risk of Weight Loss and Healthcare Staff

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Abstract

Introduction: Malnutrition is common in patients with cancer, as between 15% to 80% of all patients experience significant weight loss during disease and treatment. Patients suffering from weight loss have reduced ability to complete the prescribed treatment, reduced quality of life, and reduced survival. Optimizing nutrition intake during cancer in order to achieve weight maintenance is difficult and requires individual timely nutritional therapy. The aim of this multi method development study was to create a decision support tool which would prevent weight loss in cancer patients by supporting nutrition intake and containing relevant information to support patients as well as professionals on nutritional aspects throughout the course of treatment including rehabilitation.

Methods: An APP for decision support was developed with patient and professional involvement. Descriptive data were collected for the evaluation of efficacy as weight development and semi structured qualitative interviews with patients and professionals individually. Interviews were analyzed by qualitative content analysis.

Results: Patients maintained weight. Nutrition intake was supported in 42 patient's home by the tool. When intake was decreasing, a quick and efficient collaboration between patients and professionals made sure the right nutritional therapy decision was made and implemented. Patients and professionals were very satisfied with the system.

Conclusion: The decision support tool for nutritional therapy between patients with cancer and professionals was efficient and well liked. Patients were compliant and maintained weight and oral intake to a high extent. When oral nutrition intake decreased, a fast decision was initiated.

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Introduction

Malnutrition is a common and serious problem in patients with cancer, as between 15% to 80% of all patients experience significant weight loss during disease and treatment. The consequences of weight loss are muscle loss and impaired functioning, impaired immune system inducing infections, as well as psychological consequences, including depression, isolation and reduced quality of life [1-3]. Patients suffering from weight loss have reduced ability to complete the prescribed treatment. In radiation therapy and chemotherapy, it has been shown that poor nutrition conditions often lead to postponement or discontinuation of treatment, thus reducing the strategic effect of treatment.

Poor nutritional status specifically contributes to poor outcomes. From literature, we know that even a smaller weight loss has significant consequences for the patient's treatment efficiency, and the larger weight loss, especially the loss of muscle mass, the higher risk to survival [4-7]. Nutrition intervention and individual follow up has shown to improve quality of life and clinical outcomes in short and long term [8,9]. However, early intervention, individual patient involvement and thus compliance, treatment of nutrition impact factors and interdisciplinary collaboration, seem to be crucial in order to achieve success [1,3,10,11]. It is therefore crucial that an individually adapted nutrition course is initiated at a very early stage. Likewise, it is important that attention to the patient's nutritional state and the changing alternate need for nutrition therapy is continued throughout the entire course of treatment as well as followed up during rehabilitation [5]. Equally it is shown that nutrition and exercise are considerably coherent factors, and that patients who often cease to be physically inactive in order to save their strength, have greater muscle loss, and thus also harder to exploit the nutrition consumed efficiently [4,5,12].

By counseling patients to eat the adequate and proper diet and inverting medical nutrition therapy in due time, as well as maintaining strength and activity, one may contribute to reduce

the number and severity of complications, as well as shorten the disease and rehabilitation process. However, studies have shown that practices regarding nutritional advice and therapy during the course of cancer are insufficient [6].

People suffering from cancer and disease-related malnutrition may need to change their perception of food and their food culture in order to be able to eat sufficiently during a disease that affects the desire and ability to eat. For example, patients with cancer and disease-related malnutrition may normally aim to live a healthy life in order to prevent type 2 diabetes or cardiovascular problems, just as other people ought to do when healthy. Patients may therefore have to override the food and health perception and experience of proper healthy eating habits they have acquired, in order to fulfill nutritional requirements, when the ability to eat is lacking.

Decision Support Aids (DSA) are tools designed to present treatment choices based on the best evidence for patients, by stating the decision, describing the options, and helping people evaluate options from a personal point of view, thereby increasing the quality of the patient's decision without undermining the patient's preferences. In addition, a DSA can help health professionals in informing, structuring and involving patients in decisions. A decision support tool for cancer patients with weight loss, used by patients themselves and by the patient in collaboration with professionals throughout the course of the cancer may be able to qualify patients and professionals into the best possible dialogue on nutrition and nutrition therapy throughout the cancer course. A decision support tool for nutrition designed for cancer patients with weight loss may help the patient to pay attention to and monitor dietary intake, weight and other symptoms.

The aim of this multi method development study was to create a decision support tool which would prevent weight loss in cancer patients by supporting nutrition intake and containing relevant information to support patients as well as professionals on nutritional aspects throughout the course of treatment. Furthermore, to provide informed dialogue between patient and professionals based on patient preferences, observations and monitoring, as well as launching correct efforts and recommendations for nutritional interventions in case of impairment.

Materials and Methods

The purpose of the Public and Patient Involvement (PPI) study was to develop and implement a tool to help cancer patients with weight loss, making informed decisions about relevant nutrition therapy, in dialogue with health professionals throughout the course of treatment, from first medical visits to completed rehabilitation. Together with nine patients, eight nurses/three physicians a team of IT-technicians and the research team (authors), we developed an APP for use by patients as a single system on tablet or smart phone. The APP was developed in an iterative process in three phases, starting with analysis of needs and experience which built the basis for the development, and allowing patients and staff to test and influence the process along the way.

The APP included

A food and dietary registration module to be used by patients at home and which provides instructions to the patient about the correct individually calculated dietary intake and what the patient can eat to improve dietary intake, as monitoring and guidance to the patient. Requirements were set based on the scale of Harris-Benedict

equation. Protein requirements were calculated in the program as 1.3 g/kg/day. An arrow shows how close the patient is to the aim of the day. Suggestions are provided for achieving the goal. Far from goal shows a red arrow, which turns yellow and then green when goal is near or achieved, also including a numbered percentage.

A weight-registering module, which is also used in the calculation of individual requirements for energy and protein. Red to green relates to goals.

A nutrition impact symptom module, where patients score nausea, constipation, mouth sores, early satiety, pain, depression, and fatigue. Red to green (1-10) relates to worst thinkable or no problems.

A physical activity module encouraging physical activity and training by the APP, and patients monitor the activity undertaken in four different phases and how much time they spend during the day.

On the above, patients send information to professionals they chose to include. Patients are encouraged to do this on the day before hospital visit and/ or twice weekly. The patient connects his or her healthcare professionals (either individual or teams) including nurses, oncologists/physicians, dieticians, with a single click and these can afterwards follow the patient's entries and thus orientate themselves in the patient's nutritional state, dietary intake, discomfort and activity level continuously and be prepared for the meeting with the patient. For professionals we developed a website to gather patient information as listed below. Professionals should prepare themselves for the meeting with the patient, with the information provided, in order to give individual and informed advice on therapy actions and support interaction on decisions.

In the information library module, the patient finds explanations and relief suggestions-housing advice, as well as information about the importance of not losing weight during treatment and maintaining physical activity. Similarly, the patient in layman's language finds information about treatment options for weight loss.

We called the APP "NutriDia" reflecting nutrition dialogue between patients and professionals.

Data were collected for the evaluation of results as weight development and semi structured qualitative interviews with patients and professionals individually. Interviews were analyzed by qualitative content analysis [13].

Ethical considerations

The patients signed informed consent prior to participation. The Ethical Committee of Region North Jutland, Denmark had no objections to the study.

Results and Discussion

We aimed to primarily include patients with head and neck cancer as well as gastro intestinal cancer. This was due to the assumption that these patients would be moreover able to represent all nutritional challenges. Two other cancer patients were included, as they had heard of the APP from their treatment team, who found they would benefit from inclusion. Overall 101 patients were consecutively screened for, and 51 patients agreed to participation. Of these, nine patients were solely included in the development process, and 42 patients were included in the intervention period. The decision support tool was used by patients and the health professionals throughout the patient's treatment course, based on Aalborg University Hospital. Departments involved were the Oncology treatment Departments, including

Figure 1: The NutriDia APP surface.

Table 1: Demographic information for participants using NutriDia during the intervention.

Demography N=42	
Gender (men), n (%)	28 (66.0 %)
Age, Mean years (SD)	58 (11.2)
BMI, Mean (SD)	25.5 (2.7)
Disease Location	
Upper Gastrointestinal Cancer (cardia, pancreas, oesophagus, ventriculi)	14
Lower Gastrointestinal Cancer (Colon, Rectum)	10
Head/Neck and Tongue	16
Others	2

Table 2: Weight development from start to end of the use of NutriDia.

Weight balance N=42	Number of patients	Mean difference Kg (SD)
Maintain	16	0 (0)
Weight loss	14	1.08 (2.3)
Weight increase	12	0.55 (1.14)

radiation therapy, chemotherapy and surgery. Furthermore, patients used the system with other health professionals during their cancer course, including in conjunction with clinicians in the rehabilitation centers, and in general practitioners. One patient used it in another hospital due to transferrable to another Department of Oncology who took good care of patient and equipment, and found it valuable and easy to follow.

Figure 1 shows the front page of the patient's APP.

Demographic information for patients who used the tool during their therapy after implementation of the final tool is shown in Table 1.

The 50 patients considered potential candidates for NutriDia, but who ended up not participating were overall characterized with lack of profit for additional information, lack of compliance, lack of IT capabilities, and poor general condition. Of these 14 were included but chose and were supported to drop out after a few days.

The included patients were to a far extent able to maintain weight, as sixteen patients' maintained weight throughout the five months intervention period and the fourteen who lost weight lost remarkably little. Furthermore twelve patients slightly gained weight during the period. More than this, some patient lost or gained slightly for a couple of days, but managed to restitute within the course of treatment. Weight development is shown in Table 2.

Nutrition intake was noted for all patients, and was on average sufficient for the individual for the overall group. Thirteen patients who had an average lower average oral intake of minus 356 kcal/day (40 kcal to 1020 kcal) were supplemented with either enteral or parenteral nutrition. Eighteen patients had an increased intake of 275 kcal/day (30 kcal to 557 kcal).

Qualitative interview findings

NutriDia provides patients and health professionals with a sound basis for common nutrition related decision-making, based on the following features:

The patients were very eager to monitor ingested meals, weight, symptoms/discomfort and activity level in. In addition, the patients found they enhanced knowledge about nutrition and nutritional therapy options, reasons for discomforts and how to find relief for these.

Patients describe the tool as contributing to structure, control and overview, and to improve their ability to optimize daily intake of energy and protein. Patients always followed the scale of the app's cover page, which illustrates how much the individual was missing out of his needs.

The decision support tool has helped prevent further weight loss in patients of which a few had lost weight before the start of the cancer treatment course. This may be explained by the motivational factor highlighted by the participating patients, especially regarding the knowledge of and interest in their nutrition and dietary challenges, which they felt helped them to realize questions they had for the professionals and to find good solutions together with the staff.

The results show broad satisfaction with the simple and clear design in the decision support tool, highlighting the colors including the traffic light system. The color codes where the patient achieves "yellow" at acceptable energy intake and "green days" at target achievement was described as being crucial to the patient's focus on eating sufficiently, as well as continued the feeling of profit and want to monitor almost daily. The color codes thus support the motivation to eat, which all patients express. Patients express that NutriDia has led to increased knowledge of the nutritional content of food, especially in terms of protein and calorie content. Particular attention was paid to protein intake-since patients found the APP gave them the opportunity to follow their protein target and teach them which foods contain a lot of protein. Many patients referred to increased knowledge as they thought protein density was only found in meat and dairy products, which didn`t necessarily taste well for the time being. In addition, patients point out that NutriDia is a good tool for adjusting the intake of calories and proteins and that the app has helped to give them an overview of their weight. Finally, several patients are satisfied that NutriDia suggests what food the patient could add to the diet, and that this may be motivating for patients to try out food that they have not tried so far. As one patient said:

"I actually had no sense of the whole idea of calories and protein. Have never ever needed it before. I have only eaten when I was hungry. Now I have learned what I need. And it works really well that you can see how much you've got and how much you need. The nurse praised me this morning, because she could see that I was doing well. And you also like to be praised. I get these ideas (push messages, ed.) to what I can eat in the evening. Ice and so on. I like this feature".

Patients expressed the feeling that they were contributing to the treatment and that the professionals were well-prepared for their meetings with regard to the side effects of cancer treatment and nutritional problems. This reinforces one of the goals in NutriDia; to increase patient involvement in the course of treatment. Patients experienced great satisfaction by actively engaging in the otherwise powerless situation that accompanies cancer diagnosis, including loss of power and desire to eat.

The patient information library contributed to the informative goal of the tool, where patients became more aware of their own side effects, but also about relief suggestions.

Several patients emphasize that NutriDia's functions are supportive in relation to the dialogue the patient has with the professionals, including doctors, nurses and dieticians. The registered entries in the app acted as a starting point-for the dialogues and consultations the patients had with the professionals. Several patients described feeling confident in knowing that the professionals could follow the entries the patients made at home. In addition, several patients expressed that the professionals made use of the inputs that patients had entered into NutriDia by starting from the specific issues entered, for example regarding fluctuating weight, nausea, side effects of treatment i.e., One patient refers: "They encourage me now that it is time for me to do something about these nutritional supplements and such things". "Now you've lost a bit, so now you have to go ahead and try it".

Only one patient found that her entries were not used with the Oncologist, and that the Oncologist showed less than no interest towards nutrition or her losing weight. Se however had help from the nurses.

Main results from interviews with professionals

Professionals found that NutriDia motivates more patients to consume the required amount of calories and proteins as well as their weight. In addition, they found that the app gives patients a feeling of self-control, which many patients can enjoy in a situation where may feel out of control.

"I find we catch them earlier because they themselves get into the weight curve. So I think it becomes very visual for them (patients), how fast it can go and then they do not get the huge weight loss" (Nurse, Radiation Therapy).

"I also think that once they've got the APP, they are much more aware of getting up to the full dose" (Nurse, Radiation Therapy).

"I've heard patients say they get a pop-up 'reminder, "you're behind goals". It is a big help for many of them" (Dietitian, Oncological Day Care)

Doctors, Nurses and Dieticians use data from NutriDia as a basis for dialogue with patients. In addition to facilitating dialogue, more professionals use data from NutriDia to qualify focus in each conversation, both before and during the consultation.

"We talked out of NutriDia, where I could see that the patient met her need for protein and energy, and she had actually taken two of the kilos she has lost" (Dietician).

"It's a good tool before consulting to see what's really going on and how she is taking the oncology treatment" (Doctor).

NutriDia makes it easy to involve the patient actively when a common goal is to be set.

"I like it because we can look at the entries together and agree that this is the time to act on this or that-it is more like we are in it together. For instance the patient I talked too yesterday, who was less reluctant to tube placement, than I would have expected" (Oncologist).

All informants agree that NutriDia gave them a quick overview of their patients in the morning. The nurses in the radiation therapy used NutriDia to get an overview of the patients who came to treatment that day when they met in the morning:

"I go in and look in the morning and see; How are the different patients I have today, how is their weight coming along?" (Nurse, Radiation Therapy)

It's quick to get an overview of who's in bad shape-, the weight goes down and nausea rises, so I'm prepared for the patients-while there may be nothing with some of the other patients. So it gives me that fast-paced overview" (Nurse, Radiation Therapist).

Primary sector: NutriDia was well received in the primary sector including rehabilitation, and was predominantly used by dieticians who found it of great relevance. In rehabilitation there is most often more time for the individual patient, and NutriDia rapidly gained a significant role in the contact between the patient and the healthcare professional. In addition, it was described by professionals that NutriDia in a new way allowed for a slightly better "hand in hand" with the patients between appointments. NutriDia in rehabilitation was often used to assist with the withdrawal from enteral nutrition and nutritional supplements, when the patient monitored increasing weight and better intake.

Overall, NutriDia was well received and lived up to expectations. The only draw-back was the lack of integration into the electronic patient journals, which was not included in the project due to data safety.

In this PPI multi method development study, we included no group for comparison. Following, we are not able to say if the results achieving weight as well as protein/energy intake maintenance may have also been possible with other means and methods. Meanwhile, the development rose out of patient and professional experiences and perspectives, adding to the relevance of the actual intervention [14]. Furthermore, the tool gave room for an active and very individualized approach to nutritional therapy, which has earlier been shown efficient by other methods [5,15]. This study supports the finding of the Cochrane review, which found that people exposed to decision aids feel more knowledgeable, better informed, clearer about their values, and with a more active role in decision making [16].

Supported by NutriDia, patients were able to maintain weight and thus that were give improved conditions for going through oncology treatment without complications related to nutritional risk [4,5,12,15,17]. NutriDia well managed to engage patients in their own nutritional route and therapy, and promoting shared decision making between professionals and patients. This and the ability of

NutriDia to interact in patients lived daily lives may be an important link to enhancing better compliance to nutritional therapy.

Conclusion

The NutriDia decision support tool, which was built with patients and health professionals, prevented weight loss in 42 Head and Neck and GI cancer patients. Its features including monitoring of nutrition intake and nutrition impact symptoms, motivation and information facilities, supported nutrition intake and provided a sound basis for patients and their health professionals in the dialogue on nutritional therapy, throughout the course of treatment.

Acknowledgement

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