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POLICY AND PRACTICE

Patient education and self-management support for chronic disease: methodology for implementing patient-tailored therapeutic programmes

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ABSTRACT

Chronic diseases are characterized by long-term care, primarily provided by the patients themselves, and as such, patients must be trained in managing their chronic condition. Chronic patient education and self-management support programmes must consider the patients' specific educational needs, set learning targets and use adapted methods to deliver a therapeutic education. A patient centred, psychosocial and culturally sensitive approach combined with interdisciplinary teamwork and a motivational environment are key elements of such programmes. This article presents the innovative programme and methodology Geneva University Hospitals' Service of Therapeutic Education for Chronic Diseases is applying to organize patient education and provide self-management support.

Keywords: PATIENT EDUCATION, SELF-MANAGEMENT SUPPORT, THERAPEUTIC PATIENT EDUCATION, CHRONIC DISEASE CARE AND MANAGEMENT, DIABETES AND OBESITY MANAGEMENT PROGRAMMES

INTRODUCTION

The care and management of chronic disease patients is a major health concern at all levels of the health system. Chronic illnesses impose a large burden on health systems as they constitute a major part of care providers' activity and have an immense impact at patient level due to the requirement of daily care *(1)*. Management of hypertension, cardiovascular disease, diabetes, obesity, mental illnesses or any other chronic condition requires substantial patient involvement alongside the availability of care providers and good coordination of care between several health specialists. Hence, the patient takes on the role of the primary care provider; identifying, monitoring and managing their respective condition around the clock, from daily injections and wound care to appropriate food choices and sufficient physical activity for example, depending on the circumstances. The WHO's Global Action Plan for the Prevention and Control of Noncommunicable Diseases (NCDs) 2013-2020 recommends "empower[ing] people with NCDs to seek early detection and manage their own condition better, and provide education, incentives and tools, for self-care and self-management, based on evidence-based guidelines, patient registries and team based patient management including through information and communication technologies such as eHealth or mHealth" *(2)*. Patient education and support in managing and living with their condition are prerequisites in helping patients dealing with daily care, providing capacity-building to face daily management challenges such as daily injections, wound care, choice of food or implementing enough physical activity. The Service of Therapeutic Education for Chronic Diseases at Geneva University Hospitals has been applying innovative patient therapeutic education methods for more than thirty years, promoting a patient centred, psychosocial and culturally sensitive approach combined with interdisciplinary teamwork. This article presents some of the patient education and self-management support programmes this Service provides.

ORGANIZING PATIENT EDUCATION AND SELF-MANAGEMENT SUPPORT

As chronic disease patients are themselves the primary source of their own care, they require training to best perform their role, as would be expected of any health provider, in order to ensure the care delivered is appropriate and effective. The objectives of patient education and self-management support programmes are that *(i)* they are tailored to a patient's individual medical needs in terms of their educational content, *(ii)* shared goals are established between the care providing team and the patient, *(iii)* the educational methods used are tailored to the patient's education level, culture and learning style preferences. The overall goal of such programmes is to transform teaching/training into therapeutic education; where education forms a vital part of the treatment regime. It relates to the Chronic Care Model for which self-management support is a key element in generating the "productive interactions between a prepared, pro-active team and an informed, activated patient" *(3)*. The therapeutic educational programmes are based on the Therapeutic Education Framework *(4)* and start with a medical educational needs assessment, which is a discussion session shared between the medical doctor, members of the care team such as nutritionists, nurses or psychologists, and the patient *(5)*. The patient explains what their main health concerns are and care providers attempt to guide them in dealing with their concerns. The needs assessment also highlights skills to be acquired and forms the basis for setting and agreeing on learning targets between the patient and medical educator team. The next step is to tailor the programme to the patients' specific needs; co-constructing and then running an educational project between the patient and care provider, with the educative methods used adapted to the patient, which enables the care objectives to be reached. The last step is an evaluation process, which is important in measuring the efficacy of the implemented programme. The establishment of a motivational environment is required throughout to encourage the patient to apply and pursue the knowledge and skills acquired during programme, in their own surroundings.

METHODS

Patient education programmes are based upon the specific needs of patients as identified through the above described educational needs assessment meetings, which each patient attends upon registration to either the obesity or diabetes programme. These meetings allow for open discussion about health concerns and the identification of various educational areas that might be relevant to the patient, such as food management or diabetes complications for example. After this process, the patient enters into a specific programme based on their needs. Structured programmes take place over half a day, one day or five days, depending on the patient's choice and programme availability. The education team includes doctors, nurses, psychologists, nutritionists, art therapists, researchers, and education specialists. Having different care providers/specialists altogether to discuss the patient's case helps create a common understanding of a patient's health issues, thus the interdisciplinary programmes can be better tailored from the information shared (identification of the patient's educational needs, setting objectives, carrying out training, evaluation of skills acquired). Patient-selected, innovative and participative workshops along with the more traditional individual medical interview sessions allows for the establishment of a motivational environment. Limited use of lectures and fostering small group workshops helps to empower patients in working on their specific needs in terms of knowledge and skills acquisition. Several methods are implemented to allow for this acquisition: the workshops, physical activity sessions *(6)* (walk into town or in parks, going to the gym, cycling, etc.), nutritional support *(7)*, (lunch workshop, supermarket shopping, cooking class, etc.), art therapy *(8)* (through many artistic branches such as music, painting, theatre, dance *(9)*, clay work, etc.), and gardening therapy *(10)*, among others. Individual sessions are important to carry out medical follow-ups (glycaemic control, treatment adaptation, prescription renewal, etc.) and to offer psychological support and therapy. Patients share their experience of the therapeutic education programme through group sessions, which are led by a specialist and aim to summarize knowledge and skills learned, as well as to build group motivation.

CHRONIC DISEASE MANAGEMENT: PATIENT THERAPEUTIC EDUCATION PROGRAMMES

DIABETES EDUCATION AND SELF-MANAGEMENT SUPPORT: HALF-DAY, FULL-DAY, OR FIVE-DAY PROGRAMMES

The **half-day programme** includes a welcome/introduction session, two different workshops on themes related to diabetes care, for example the complications of diabetes (kidney, eyes, erectile dysfunction, etc.), and a common session with patients

reporting on what they have learned from their respective workshops to the entire group with help from a care provider/educator (nurse or doctor). The workshops use a learning-by-doing approach; if the patient has difficulties in managing insulin injections for example, practice sessions will be offered. The **full-day programme** extends on this by including a hands-on learning lunch break, coined therapeutic mealtime, on nutrition (hidden carbohydrates/fat, protein sources, low versus high glycaemic index food etc.), based on the patients' taste preferences and food choices from a buffet lunch. Prior to the lunch, workshop participants are gathered in the group feedback session, allowing a care provider team meeting to be held in parallel. This interdisciplinary team meeting is critical for sharing and discussing each patient with all team members, in order to agree on their individual needs and to set specific objectives. Thereby patients can be orientated towards relevantly themed workshops in the afternoon session along with other patients with similar educational needs. The bringing together of patients helps each individual patient to raise and share their difficulties and find solutions to any problems faced; the peer learning technique is recognized as an important educational tool. The care provider acts as a mediator in the group sessions and validates efficient strategies implemented by patients and delivers simple take home messages. A final group learning session led by the care provider then summarizes the day's teaching and experiences. Individual interviews that take place on the day with each patient can help guide the setting of objectives and to agree on skills to implement by the next set appointment, as well as to settle any medical issues related to disease management (medical prescription, etc.). The **five-day programme** offers more opportunities for tailoring to individual needs, with the programme customized through further need-specific workshops and additional monitoring with several patient-to-care provider sessions. The three main topics covered in the five-day programme are *(i)* diabetes overview with glucose monitoring, hypoglycaemia management and the complications of diabetes, *(ii)* nutrition, and *(iii)* physical activity. The programme starts on a Monday with the above described educational needs assessment in order to set learning targets and guide the tailoring of the workshops. Throughout the week, a self-experience based approach is encouraged and nutrition and physical activity based themes are held every day in different settings. Theoretical facts are presented initially (why, how much per week, what benefits etc.), followed by practical workshops putting patients in real-life situations, for example, measuring heart beats per minute while performing exercise (before/after cycling or walking), or choosing carbohydrate containing food according to calories needed at a buffet lunch. Individual learning sessions alternate with group workshops to allow each patient to move towards achieving their targets identified from their needs evaluation, with the help of their peers. The end of week sessions are dedicated to implementing the exercise/nutrition tips learned into the daily routine, with patients creating a personal project they need to pursue once back home.

OBESITY MANAGEMENT AND SELF-MANAGEMENT SUPPORT: FIVE-DAY OR TWO-YEAR PROGRAMMES

The obesity **five-day programme** *(10)* follows same structure as the diabetes management programme of the same length. The **two-year programme** *(11)* has a similar start to that of the five-day programme, but with the addition of iterative meeting days scattered over a two-year period, allowing patients to implement an educative project with the help of the care provider/medical educator, again based on the initial educational needs assessment. An important addition in the longer programme is the psychosocial support offered throughout the whole process. The programme is based on four themes: *(i)* medical, *(ii)* nutrition, *(iii)* physical activity and *(iv)* psychological support *(12)*. A variety of modules are offered within each theme, and are chosen by participants according to their interest (2 modules per theme), enhancing the tailored nature of the programme. Throughout the programme, a patient centred and culturally sensitive approach is followed, which takes the patient's sociocultural environment into account to help tack issues such as poverty, fat shaming or bullying, a toxic social environment or any other issue patients are facing that have an impact on their well-being. Medical support is based upon interdisciplinary care including that from a primary care physician, as well as a gastroenterologist, rheumatologist, or any other required specialist. The nutrition theme offers teaching about food and focuses on eating disorders; a positive approach is taken throughout (no restriction of food), patients are taught to acknowledge the feeling of satiety and to work on their behaviour concerning food (compulsion versus restriction). Establishing a motivational environment is again key and all medical educators are trained in motivational interviewing techniques. The physical activity branch of the programme focuses on body image and the self-perceived ability to exercise. Again, workshops include some teaching elements and self-testing sessions with practical exercises that are easy to reproduce in the patient's daily routine. Psychological support is essential in shedding light on the root cause of the eating disorder. Throughout the programme patients are accompanied in their progressive transformation, and helped to experience new situations such as dance, or innovative techniques like art therapy.

TABLE 1: FIVE-DAY DIABETES PROGRAMME

Time	Monday	Tuesday	Wednesday	Thursday		Friday	
7 am	Blood test	Welcome Blood and urine samples, treatment adaptation	Individual session (2 care providers)	Welcome	Medical team meeting	Welcome	
8 am	Breakfast						
8.30 am	Welcome						
9.15 am	Individual session (2 care providers)	Workshop: Diabetes treatment	Workshop: Physical activity	Workshop: Glycaemia reading		Workshop: according to the patient's choice and needs	
10 am	Snack	Snack	Snack	Snack		Snack	
10.30 am	Individual session (2 care providers)	Individual session (2 care providers)	Physical activity with carbohydrate need identification and compensation	Workshop: Glycaemia testing devices	Workshop: Injection sites	End of programme individual session	Nutrition: Q&A session
1 pm	Buffet lunch	Buffet lunch	Buffet lunch	Buffet lunch		Buffet lunch	
2 pm	Nutrition workshop: Carbohydrate break down and identification	Diabetes workshop: Dealing with hypoglycaemia	Workshop: Complications of diabetes	Medical consultation	Workshop: Individual project	Information about Geneva Diabetes Association	
3.15 pm	Panel session: Living with chronic disease	Nutrition workshop: Carbohydrate quantities management		End of day individual session (2 care providers)	Medical team meeting	Closing panel session	
4 pm	Patient end of day	End of day individual session: Treatment adaptation	End of day individual session (2 care providers)			End of day individual session (2 care providers)	
5 pm	Medical team meeting						

CONCLUSION

Taking charge of the chronic disease epidemic requires a holistic approach. Adaptation at governance level, as well as the re-organization of the health delivery system is needed in order to be more efficient in providing care to chronic patients. As new approaches are required, Geneva University Hospitals' Service of Therapeutic Education for Chronic Diseases has been applying innovative methods in managing and educating chronic patients to care for themselves. A patient centred, psychosocial and culturally sensitive approach combined with a hands-on education in medical care, nutrition and physical activity, in a motivational environment with a strong psychological component is key. Based on research performed and long-standing experience, techniques and methods are implemented in courses and workshops to deliver therapeutic education and accompany chronic patients in self-management, autonomy and well-being.

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