The phenomenon of self-care in chronic diseases on the example of patients with multiple sclerosis

Zjawisko samoleczenia w chorobach przewlekłych na przykładzie chorych na stwardnienie rozsiane

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Abstract

Background. The increasing number of people suffering from chronic diseases constitutes a challenge for public health specialists. Due to the limitations in the treatment of diseases of unknown etiology, patients become prone to undertake self-care. Depending on the policy, education and culture of a given country, the phenomenon may become a chance or a threat in the context of the functioning of healthcare.

Objectives. The main aim of the study was to assess the prevalence of self-care among patients with chronic illnesses as well as to determine the reasons for undertaking self-care and its duration. The authors of the study were also interested in the self-care methods and patients' conviction regarding their effectiveness.

Material and methods. The study was conducted with the use of the computer-assisted web interview (CAWI) method among 176 individuals suffering from multiple sclerosis (MS) or in whom the disease was suspected. The survey questionnaire was created at the ankietka.pl website, and was distributed in several virtual groups gathering people suffering from MS. The studied population consisted primarily of women (77%) and individuals suffering from MS for the period between several months and 20 years (77%). The average age of the respondents was 36.

Results. Almost ¾ of the studied individuals used self-care, being mostly driven by "the desire to do something for oneself" (65%) and the conviction that the conventional methods are ineffective (38%). The most popular type of self-care were dietary supplements (90%). However, it is also the form of self-care which most disappointing to MS patients. The patients also believed that conventional medicine, funded by the National Health Fund (NHF), lacked effectiveness. The effectiveness of commercial medical procedures paid for by the patients themselves was rated the highest. Thus, positive assessment of conventional treatment effectiveness in MS depends on rehabilitation, not pharmacotherapy

Conclusions. Application of self-care should be considered as one of the most important ways of satisfying the health needs of the already-ill individuals or individuals in whom MS, a severe and unpredictable disease, which frequently leads to disability, is suspected. The most common reason for the implementation of such treatment is the need to satisfy the internal need of taking care of one's health when a crisis related to it occurs or when a disease is suspected. Thanks to the undertaken action, the patients convince themselves that they are able to withhold or slow down the progress of the disease, in order maintain the functional efficiency of the organism for as long as possible.

Key words: dietary supplements, self-care, multiple sclerosis

Streszczenie

Wprowadzenie. Zwiększająca się liczba osób zmagających się z chorobami przewlekłymi stanowi wyzwanie dla specjalistów zdrowia publicznego. Ograniczenia występujące w leczeniu chorób o nieznanej etiologii skłaniają chorych do podejmowania samoleczenia. W zależności od polityki państwa, prowadzonej edukacji oraz panującej kultury zjawisko to może być szansą lub zagrożeniem w kontekście funkcjonowania ochrony zdrowia.

Cel pracy. Głównym celem pracy była ocena powszechności zjawiska samoleczenia wśród przewlekle chorych, określenie powodów i czasu jego podejmowania. Przedmiotem zainteresowania autorek niniejszej pracy były również metody samoleczenia oraz przekonania chorych o ich skuteczności.

Materiał i metody. Badanie przeprowadzono metodą CAWI wśród 176 osób chorujących na SM lub u których podejrzewa się występowanie tej choroby. Kwestionariusz ankiety utworzono w serwisie ankietka.pl i rozpowszechniono w kilku wirtualnych grupach pacjentów skupiających osoby chore na SM. Na populację objętą badaniem składały się głównie kobiety (77%), osoby chorujące na SM od kilku miesięcy do 20 lat (77%). Średni wiek respondentów wynosił 36 lat.

Wyniki. Niemal trzy czwarte badanych stosowało samoleczenie, głównie z powodu „chęci zrobienia czegoś dla siebie" (65%) oraz przekonania, że metody konwencjonalne nie są skuteczne (38%). Najpopularniejszym rodzajem samoleczenia było zażywanie suplementów diety (90%). Jednak ta forma samoleczenia najbardziej rozczarowuje osoby chore na SM. Za mało skuteczną respondenci uznali również medycynę konwencjonalną opłacaną z NFZ. Najlepiej oceniono skuteczność komercyjnych zabiegów medycznych opłacanych przez pacjentów z własnej kieszeni. Pozytywna ocena skuteczności leczenia konwencjonalnego w SM jest zatem uzależniona od zabiegów rehabilitacji, a nie farmakoterapii.

Wnioski. Stosowanie samoleczenia należy zaliczyć do najważniejszych sposobów zaspokajania potrzeb zdrowotnych osób już chorujących lub z podejrzeniem ciężkiej, nieprzewidywalnej i często prowadzącej do niepełnosprawności choroby, jaką jest SM. Najczęstszym powodem jego wprowadzenia jest spełnienie wewnętrznej potrzeby dbałości o zdrowie w momencie wystąpienia kryzysu zdrowotnego lub podejrzenia choroby. Dzięki podejmowanym działaniom chorzy realizują przekonanie, że uda się „zatrzymać" lub spowolnić postęp choroby, by jak najdłużej utrzymać sprawność funkcjonalną organizmu.

Słowa kluczowe: suplementy diety, samoleczenie, stwardnienie rozsiane

Introduction

Self-care is a social phenomenon shaped by the culture, state health policy, patients' own experiences and access to factual knowledge.[1] World Health Organization uses the terms: 'self-care' and 'self-medication'. Self-care refers to a wide spectrum of activities maintaining and preserving one's health. Among those, we can distinguish: following the rules of hygiene, proper diet, maintaining healthy lifestyle, and rational self-medication.[2] In the case of long-term therapies and recurring diseases, self-medication is also classified as "periodical or constant application of medications recommended by the physician".[3]

Self-care is particularly important among patients suffering from chronic diseases due to the fact that the diseases are responsible for 85% of all deaths in Europe.[4] More than a half of Poles (54%) complain that they suffer from long-term health problems or chronic diseases lasting at least 6 months. They are more frequently reported by women than men (57% of women vs 47% of men). The percentage of people suffering from long-term health issues increases with age.[5,6] It is worrying that ¼ of children aged 0–14 are diagnosed with at least 1 chronic disease, which poses a challenge for the public health sector in terms of preventive medicine.[5]

It should be noted that self-care interests mostly people suffering from the diseases, the treatment of which with conventional methods might be unsuccessful. It results from the unexplained etiology of those diseases, prolonged diagnostic process and the lack of access to effective and adverse effect-free treatment. Self-medication and self-care may be a display of the patient "coping" with high uncertainty regarding the course of the disease and its effects (i.e., disability). The patient puts himself or herself in the role of the "subject", who (co-)decides about the use of medications, herbs and substances which are within the range of his or her capability and controls the symptoms of the disease. In such context, self-care may be perceived as a strategy of the patient, resulting from the lack of effective prophylaxis and education[7] as well as the lack of access to factual knowledge. Self-care may also accentuate the positive aspect of being ill; the disease broadens patient's knowledge and increases their causative capability, thus contributing, in a sense, to achieving a "success" in a difficult situation. It concerns both gaining information (e.g., about new treatments) and using a therapy (e.g., importing a medication from abroad).

An example of a disease, the causes of which are not fully known is multiple sclerosis – MS (Latin: sclerosis multiplex – SM). It is assumed that its occurrence is influenced by numerous factors.[8] The disease gradually damages the central nervous system, which very often leads to disability. Patients with MS frequently suffer from symptoms such as pyramidal paresis and sensory or coordination disorders.[9] A group which is at especially high risk of MS are women. The age range within which the maximum incidence is observed is between 20 and 40.[10] The median is 23.5 years of age, and the average age is 30.

Self-care becomes particularly interesting with regard to chronic diseases. In this case, the patients themselves can assess the effectiveness of the treatment recommended by their physician, and they can (and are often allowed

to) modify the doses of their medications as well as the frequency of their administration. Through controlling the symptoms and observing the reactions, patients can add medications not prescribed by the doctor, use supplementation and change their diets and lifestyle on their own. At this point, we can already discuss the unpredictable and undesired effects of including additional medications, herbs and dietary supplements in the treatment established by the physician. These include:

– lowering the effectiveness of conventional treatment,
– postponing the decision regarding changing the conventional treatment,
– adverse reactions to combined therapy (among other things, lowering the absorption of active substances, duplications of the doses, interactions increasing the risk of damaging healthy organs and systems and so on),
– raising the authority of common knowledge (lay referral system), and even ignoring medical knowledge (the recommendations of the physician).

The authors of the article assumed that the phenomenon of self-care is particularly common among MS patients. The assumption is supported by the chronic and unpredictable nature of the disease, its higher incidence in women (who are more willing to seek medical help than men, and show responsibility for caring for their own health and the health of their families) as well as the need to alleviate the disease and its concurrent symptoms, such as: depression, spastic muscles, pain, cognitive disorders, abnormal sphincter function, or sexual dysfunctions.[7,11] The lack of complex care dedicated to MS patients urges them to deal with the disease on their own. The acknowledgement of the problem constituted the basis for the attempts to systematize the causes and methods of self-care among MS patients.

The main aim of the paper was to determine the prevalence of the self-care phenomenon and the causes for it among chronically ill patients, based on the example of people diagnosed with MS or those individuals in the case of whom the proceedings aimed at confirming or ruling out the disease are in progress. The most important element of the work was the attempt to gather knowledge on the frequency and type of procedures aimed at improving or restoring health taken up by patients on their own, and to investigate the subjective opinion of the patients concerning their effectiveness. Thanks to such knowledge, public health specialists will be able to determine the needs of patients with chronic conditions in terms of health education, and to assess the scale of risk of the occurrence of health threats, which should be prevented, in the patients.

Material and methods

The 1st part of the study project was a query of Polish and English literature on MS. The 2nd part consisted of a study conducted between February and April 2016. The study group, selected non-probabilistically, included 176 patients. The respondents were people suffering from MS or in whom the disease was suspected. Those who were diagnosed with MS constituted 77% of the study group (135 individuals). The lack of official registers of MS patients makes it impossible to create a representative group. For this reason, the authors decided not to conduct statistical inference. Despite the above limitation, it is worth noting that the study sample reflects the epidemiological picture of the population of individuals with MS, most of whom are women. The study was conducted with the use of the computer-assisted web interview (CAWI) survey with the use of an original questionnaire created at the ankietka.pl website.

The questionnaire was shared using Facebook. The target group was selected by researchers, who joined closed groups bringing together MS patients and people interested in the topic, i.e.: *MS is not a verdict, it is a disease like many others* [Polish: SM to nie wyrok, to choroba jak wiele innych], Cheerfulness in MS [Polish: Pogoda Ducha w SM], *Through Multiple Sclerosis with Cannabis* [Polish: Przez Stwardnienie Rozsiane Konopiami], *The Neuropositive* [Polish: Neuro-pozytywni], *Multiple Sclerosis – Wroclaw and the surrounding areas* [Polish: SM – Wrocław i okolice]. The core action aimed at gathering respondents was posting a request to fill in the survey on the main page of the group. Moreover, in order to disseminate the survey more effectively, the questionnaires were sent to individual members of the groupin a form of approx. 500 private messages with a request to fill it in; the questionnaire consisted of 9 parts containing 59 questions. It contained first and foremost closed questions, which made it possible to collect information regarding the frequency and types of self-care used. The 1st part of the questionnaire contained 15 questions concerning demographics. The next part was dedicated to treatment. The subsequent 6 parts contained questions concerning: the use of supplements and over-the-counter (OTC) medications, diets, herbs and hortitherapies, cannabis and its derivatives, unconventional medicine treatments, as well as out-of-pocket conventional medicine treatments. The surveyed individuals were also asked to assess the effectiveness of each type of self-care. The final panel of the survey contained questions regarding self-assessment of the physical and mental health as well as the quality of life. The questionnaire also included open questions, where the respondents could provide comments and assessments of the effectiveness of the self-care which they took up. Ninety-six spontaneous answers to 6 questions of this type were received. Some of them are presented below. A request to evaluate the questionnaire was included in its summary. Twenty-six feedbacks, in which the respondents assessed the importance of the issues addressed in the research, were obtained.

Results

Sample characteristics

The study sample, which constituted the basis for the study, consisted of people who declared that they were either suffering from the disease or it was suspected in them. Women constituted 77% of the study group (n = 136) and men 23% (n = 40). The average age of the respondents was 36.5 years (women 36.1 years; men 37.7 years), and the median was 33.5 years. More than a half of the respondents stated that in their case MS was relapsing-remitting (60.2%) and 19.3% of the respondents were diagnosed with the progressive type of the disease. In 5.1% of the respondents, the disease was suspected. In 66.5% of the diagnosed patients, the duration time of the disease was up to 10 years. More than 1/3 of the study participants (37%) declared that they suffered from another chronic disease (a cardiovascular disease, thyroid disease or depression). Characteristics of the disease is presented in Fig. 1–6.

Popularity of self-care

Almost 3/4 of the respondents admitted taking up self-care (74%). Men and women used self-care equally. No significant differences were observed considering the place of residence (self-care was taken up by 48% of people living in the country and 83% of people living in cities of >500,000 residents) and education (self-care was used by 58% of people with vocational education and 84% of people with higher education). The age of women who decided who take up self-care is lower than the average age in the sample, and equals 35.6 years (men: 36.1 years). Thus, younger people with a higher degree of education, living in large cities, are more willing to take up self-care (Table 1).

Reasons for taking up self-care

The factor that determined taking up self-care was the need to satisfy individual needs, defined as "the desire to do something for oneself" (64.9%). Almost 40% of the respondents were convinced that conventional methods would not improve patient's functioning (38.2%). Another reason for using self-care were errors in communication – lack of comprehensive information from the physician (27.5%) – Fig. 7. High cost of conventional treatment and its cumbersomeness (adverse effects) also constituted important reasons.

The question regarding the reason for taking up self-care showed differences in the motivation of particular patients. It turns out, however, that the most important factor is the strong need to "do something for oneself", which constitutes an element of adapting to new health conditions, when the patients believe that they are able to control the symptoms and the course of the disease. The need occurs regardless of the duration time of the disease, and the authors of this work believe that it should be associated with the ailments occurring most commonly in the patients (fatigue, reduced concentration, motor coordination disorders, etc.).

Types of self-care

The most popular type of self-care among people with suspicion or diagnosis of MS were dietary supplements (90.1%). Approximately 62% of the respondents were on a special diet, and another 55% paid for procedures offered within the framework of conventional treatment (Fig. 8). Almost 45% of patients using self-care at the same time used complementary and alternative medicine (CAM) methods, herbal medicine (44%) and cannabis derivatives (29%).

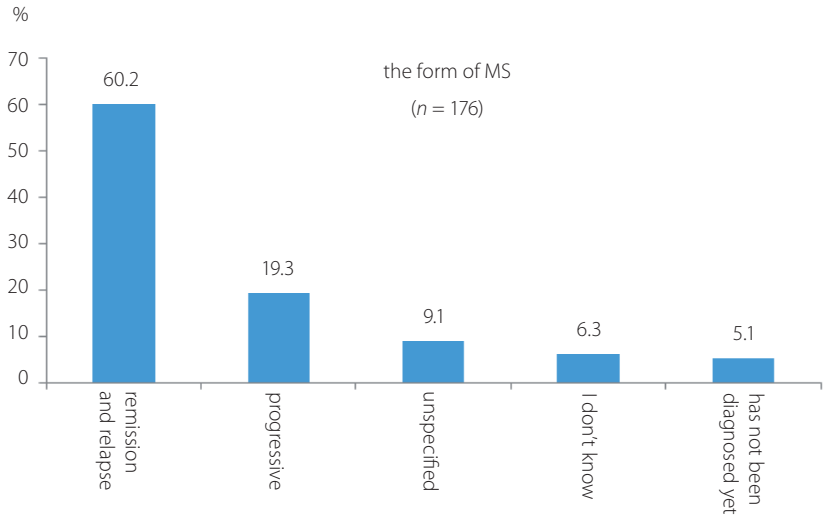

Fig. 1. Study sample characteristic: the form of MS

Ryc. 1. Charakterystyka próby: postać SM

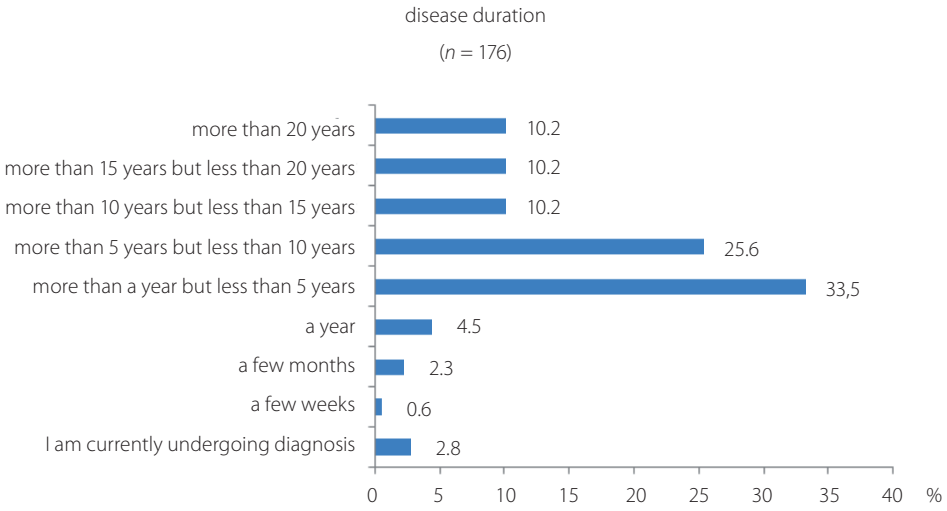

Fig. 2. Study sample characteristic: duration of the disease

Ryc. 2. Charakterystyka próby: czas trwania choroby

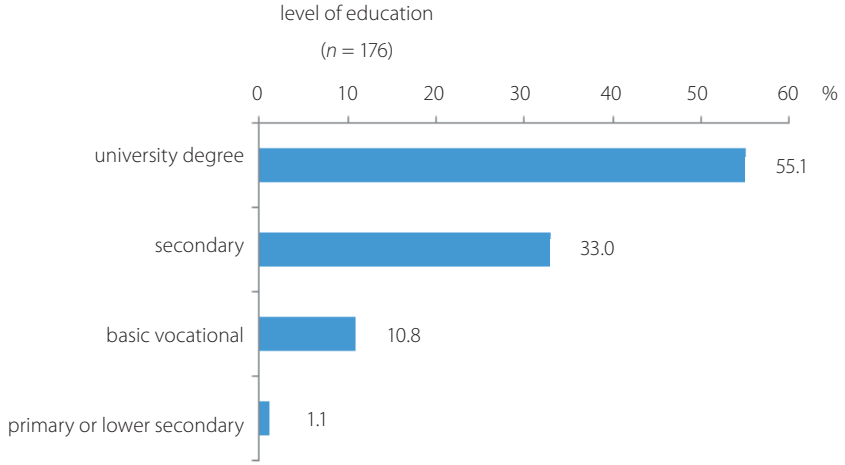

Fig. 3. Study sample characteristic: education

Ryc. 3. Charakterystyka próby: wykształcenie

Fig. 4. Study sample characteristic: health assessment

Ryc. 4. Charakterystyka próby: ocena stanu zdrowia

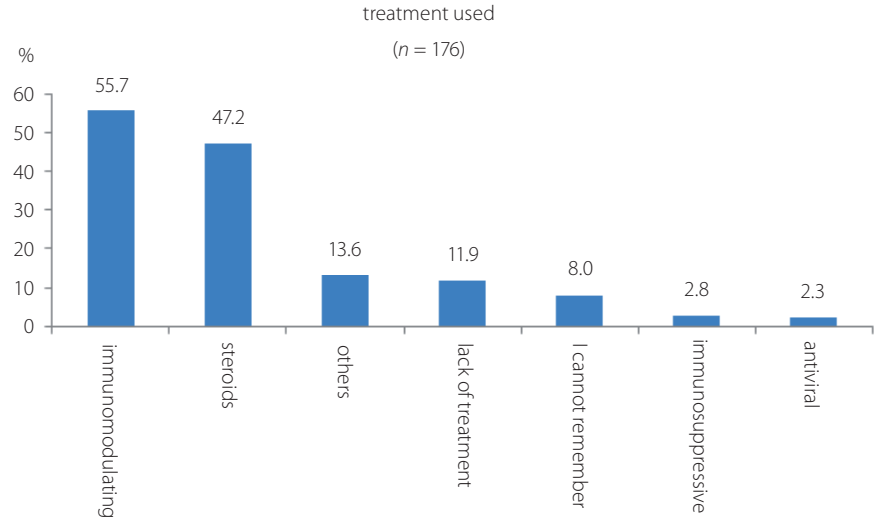

Fig. 5. Study sample characteristic: treatment used

Ryc. 5. Charakterystyka próby: stosowane leczenie

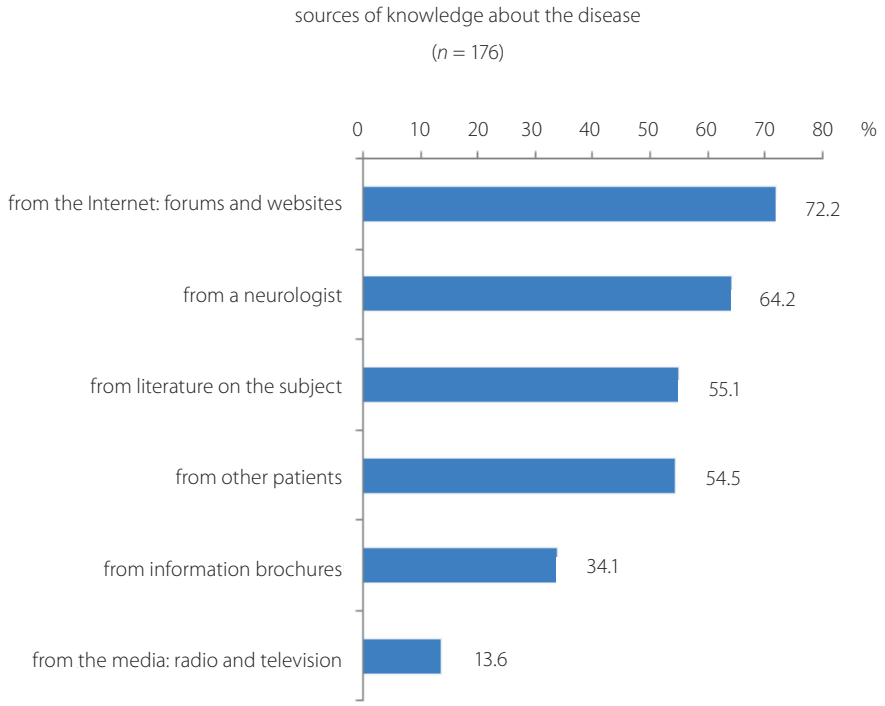

Fig. 6. Study sample characteristic: sources of knowledge about the disease

Ryc. 6. Charakterystyka próby: źródła wiedzy o chorobie

Dietary supplements and over-the-counter drugs

Dietary supplements and OTC drugs constituted the basis for self-care among patients. The respondents used mainly: vitamin D (87.3%), magnesium (72.9%) and B-group vitamins (69.5%). Preparations containing n-3 and n-6 acids, oils, and vitamins: K_2, A and E were also popular (Fig. 9). Almost 1/5 of the patients (17%) imported OTC drugs and dietary supplements from abroad.

The knowledge regarding supplements comes primarily from other patients. Almost every 2nd patient (49.2%) admitted that another patient suffering from MS played an important role in making such decision. Less respondents indicated people from the internet forum for MS patients (43.2%), and only 30.5% of the respondents provided that they had found and used a given treatment on their own.

Patients combine supplementation with other forms of self-care. In the group of the respondents taking OTC

Table 1. Respondents using self-care according to age, level of education, place of residence, and duration of illness

Tabela 1. Respondenci stosujący samoleczenie wg wieku, poziomu wykształcenia, miejsca zamieszkania oraz czasu trwania choroby

Feature	Persons using self-care (n = 131)	
	women[a] [%] (n = 101)	men[b] [%] (n = 30)
Education		
primary	0.0	0.0
basic vocational	50.0	80.0
secondary	66.7	62.5
university degree	84.6	84.2
Place of residence		
countryside	42.1	62.0
town <20,000 inhabitants	75.0	50.0
town 20,000–100,000 inhabitants	75.0	100.0
city 100,000–50,000 inhabitants	75.0	87.0
city >500,000 inhabitants	85.4	75.0
Disease duration		
during the process of diagnosis	100.0	0.0
less than a year	70.0	60.0
more than a year but less than 5 years	77.3	86.7
more than 5 years but less than 10 years	77.1	70.0
more than 10 years but less than 15 years	61.5	60.0
more than 15 years but less than 20 years	76.5	100.0
more than 20 years	54.5	71.4

[a] average age: 35.6 years.
[b] average age: 36.1 years.
n – number of the analyzed characteristic in the sample.

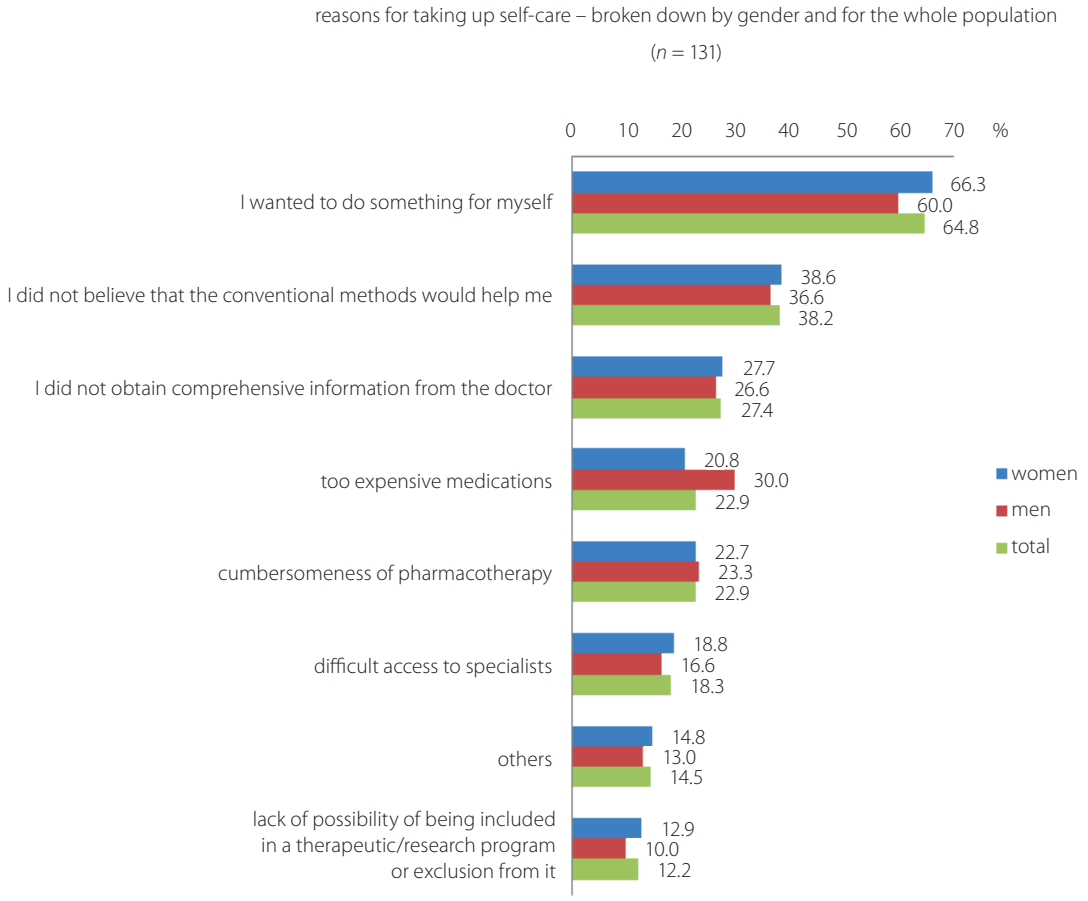

Fig. 7. Reasons of undertaking self-care

Ryc. 7. Powody podjęcia samoleczenia

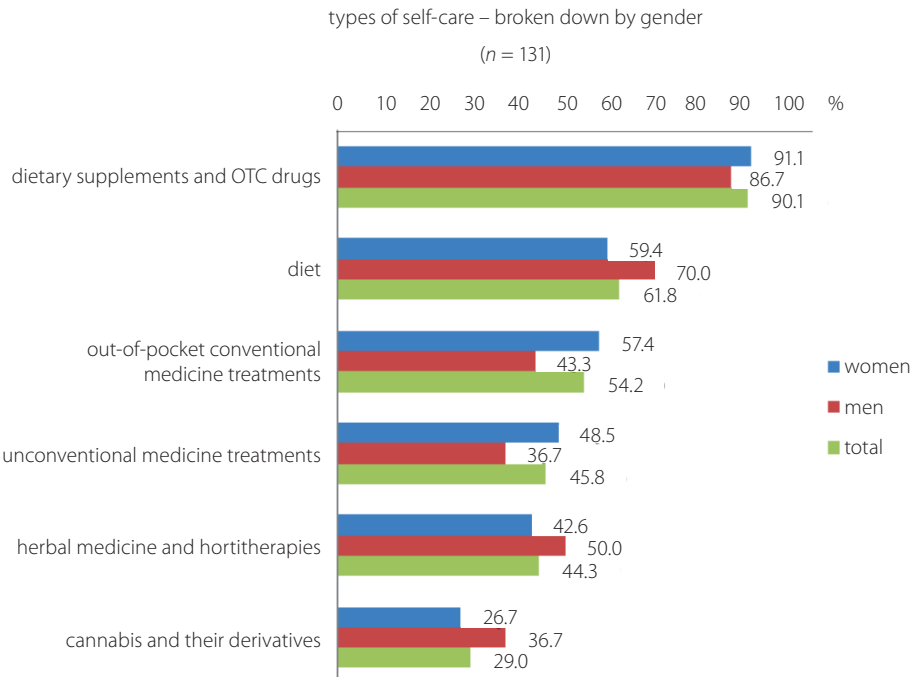

Fig. 8. Methods of self-care

Ryc. 8. Rodzaje samoleczenia

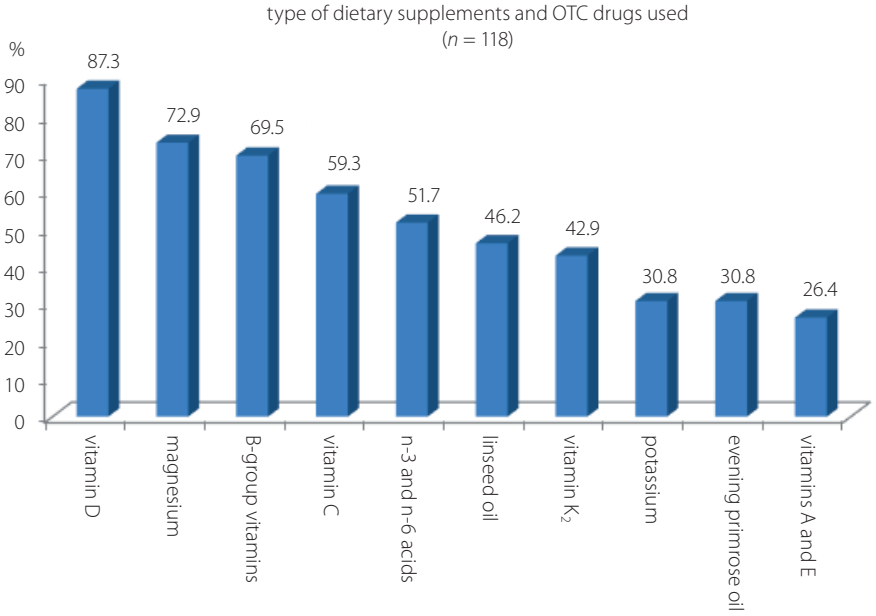

Fig. 9. Types of diet supplements and OTC drugs used

Ryc. 9. Rodzaje stosowanych suplementów diety i leków OTC

medications and dietary supplements, most (64%) were simultaneously following a diet and using out-of-pocket conventional medicine (53%).

Diet therapy

The 2nd most frequently mentioned method of self-care was diet – 62% of participants declared following one. Over 44% chose gluten-free diet, 1/3 of the respondents limited sugar consumption (34.5%) and 32.1% followed other diets, not listed in the questionnaire. Among other diets, the respondents listed: Dr. Wahls's diet protocol, paleo diet and Dr. Ewa Dąbrowska's diet. Only every 3rd respondent following a diet (34.6%) suffered from a diagnosed food intolerance or allergy, for example to gluten or dairy products. In order to maintain their health or alleviate the symptoms of MS, the respondents consume: fruits and vegetables (85.5%), seeds and nuts (72.8%) and condiments (63%), such as curcuma, garlic, ginger, cayenne pepper, cinnamon, etc. As many as 93% of the re-

spondents following a diet were simultaneously taking OTC drugs and dietary supplements.

Conventional medicine – out-of-pocket treatments

Over a half of the respondents (54.2%) using self-care also used conventional medicine, for which they paid on their own. Most of the respondents paid for physical rehabilitation (77.5%) and massage (70.4%), and almost a half – for cryotherapy treatments (46.5%). As much as 87% of the respondents using conventional medicine treatments, for which they paid on their own, simultaneously used OTC medications and dietary supplements. Most likely, the rehabilitation procedures recommended by the physicians turned out to be insufficient to maintain the desired level of control over the progress of the disease. Many people try to prevent or delay the progress of the disease on their own, as it inevitably leads to disability and dependence of the patients.

Unconventional medicine

While independent use and self-funding of conventional treatments may indicate irregularities in the care for MS patients (insufficient number of refunded treatments), the use of unconventional therapies may indicate negligence of the medical services system in non-clinical aspects of the disease, such as comfort of functioning, the quality of life, as well as social and spiritual aspects of an incurable disease.

Forty-six percent of patients admitted to using this form of self-care. Women chose unconventional therapies more often than men (48% of women and 37% of men using self-care). Approximately 3/4 preferred massage, and almost a half of them – yoga (45%) and bioenergy therapy (43%). Women chose massage and yoga much more often than men, whereas men chose massage and bioenergy therapy. Almost all people using unconventional medicine also used OTC medications and dietary supplements (93%). The data are depicted in Fig. 10.

Herbal medicine and hortitherapies

A total of 44.3% of the respondents used herbal medicine and hortitherapies. Men were more willing to use this method (50% of men vs 42% of women). The respondents most frequently chose cistus (67.2%), green tea (56.9%), ginger (55.2%), and mint (46.6%). Data are presented in Fig. 11. In the group preferring the method, the respondents also used OTC medications and dietary supplements and followed diet therapy.

Cannabis and their derivatives

Almost every 3rd respondent consumed cannabis and their derivatives (29%). Men are slightly more willing to use this type of self-care (36.7% men vs 26.7% women). Less than 6% of all respondents consume them constantly or frequently. A half of the respondents use cannabis and its dried derivatives. More than 1/4 of them declare consumption of cannabis oil (26.3%) and hashish (26.3%). Men more often choose dried cannabis derivatives (20%) and hashish (7.5%). A small percentage of women prefer dried cannabis (8.1%) and cannabis oil (5.9%). In the study, it was observed that the higher the education level of the respondents, the higher the probability of the consumption of cannabis and its derivatives. The study also showed that younger respondents used this form of therapy more often. The average age of patients using cannabis was 31.8 years, and of patients who did not use this type of treatment – 37.3 years.

Most respondents using cannabis and its derivatives (95%) also used OTC medications and dietary supplements and followed diet therapy (79%).

Assessment of treatment effectiveness

The comparison of the effectiveness of various forms of MS treatment (Table 2) yields interesting results. While the respondents rated the effectiveness of conventional pharmacotherapy as quite low, their assessment of the effectiveness of conventional treatments (non-pharmacological) was good. It may support the thesis that making medical decisions (regarding treatment method) on one's own influences the assessment of treatment effectiveness. The respondents give high ratings to those therapies which they chose and paid for on their own. It is equally reasonable to state that the MS treatment program in Poland (as well as treatment programs of other rare or cost-intensive diseases) leaves much to be desired and takes poor account of patients' needs (it primarily concerns the lack of free rehabilitation, which delays the occurrence of disability).

The respondents rated the effectiveness of commercial medical treatments, mainly motor rehabilitation and massage (44% of patients using these treatments observe considerable improvement in their health) best. Conventional treatments, which patients view as necessary to maintain good health, and which have to be paid for by the patients themselves, are perceived as more valuable and effective. It seems that positive evaluation of conventional treatment effectiveness in MS depends on rehabilitation, not on pharmacotherapy. This form of self-care also makes it possible to protect the identity of the patient as a person controlling the symptoms and the progress of the disease (prevention of disability).

The most popular method of self-care – supplementation and OTC drugs – was evaluated as not very effective. Many people are not able to assess their actual influence on their well-being (32%), which probably results from using preparations without proven effectiveness (with regard to the ailments related to MS), of low quality (cheap, from non-pharmacy sources) and uncertain indi-

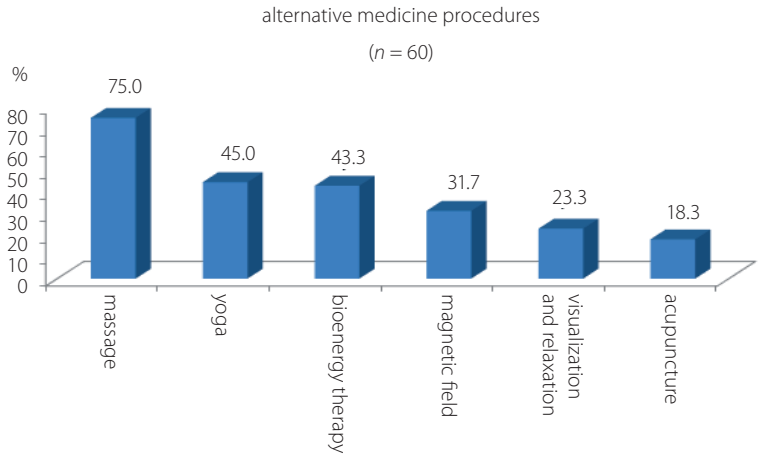

Fig. 10. Alternative medicine procedures employed in self-care

Ryc. 10. Zabiegi medycyny niekonwencjonalnej stosowane w samoleczeniu

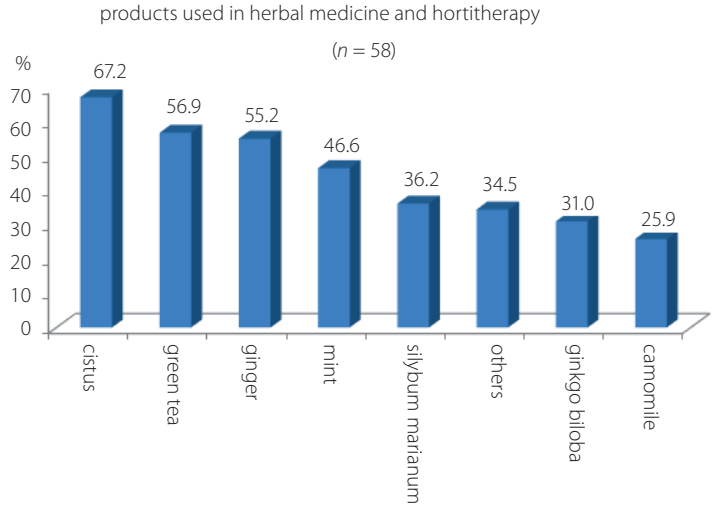

Fig. 11. Products used in herbal medicine and hortitherapy

Ryc. 11. Produkty stosowane w ziołolecznictwie i terapiach roślinnych

Table 2. Self-observation of health improvement regarding selected forms of self-care

Tabela 2. Samoobserwacja poprawy stanu zdrowia w stosunku do wybranych form samoleczenia

Form of treatment	Assessment of treatment effectiveness			
	yes, I noticed an improvement [%]	I noticed a slight improvement [%]	I did not notice an improvement [%]	it is hard to say [%]
Conventional medicine – out-of-pocket treatments (*n* = 71)	43.7	42.2	4.2	9.8
Unconventional medicine (*n* = 60)	40.0	31.6	6.6	21.6
Diet therapy (*n* = 81)	30.8	37.0	8.6	23.4
Cannabis and its derivatives (*n* = 38)	39.5	26.3	23.7	10.5
Herbal and plant medicine (*n* = 58)	22.4	37.9	22.4	17.2
Dietary supplements and OTC medications (*n* = 118)	22.9	32.2	12.7	32.2

cation of the duration time of supplementation. Because supplements are not therapeutic agents, observing their effectiveness can be subjectively difficult, especially if the condition of the patient is poor.

Almost 44% of patients using unconventional medicine observed significant improvement in their well-being, whereas in the case of patients using cannabis it was 40%. Therefore, the types of treatment which are not supported by the medical community are assessed as most effective. It is worth noticing that the first medication made of medical cannabis – recommended to be used in the case of, among other diseases, MS – was introduced to the Polish market as late as in November 2018.

Discussion

Almost 3/4 of participants declared using self-care. Similar results were obtained by Mirowska-Guzel et al.[7] On the basis of the conducted studies, she observed that the use of self-treatment was declared by 68% of respondents. Varied forms of self-care used by the participants of the studies described in the article result from low evaluation of the effectiveness of conventional treatment, limited access to pharmacotherapy and difficulties in access to rehabilitation. Using various forms of self-care results from noticeable and/or confirmed progress in disease treatment as well as the need to "do something for oneself", understood probably as actions aimed at improving the quality of life and preventing (delaying) disability and dependence, which satisfy the need of control over disease.

The reasons for undertaking self-care can be divided into those which result from the organization of healthcare system and communication errors that occur in it, and those which are based on the beliefs and needs of patients. The reasons for self-care resulting from systemic errors in healthcare are: difficult access to healthcare services and high cost of conventional treatment. Errors in communication between the medical staff and patients include treating patients like objects and failure to adjust the messages to their recipients.[12] The reasons for self-care resulting from patients' beliefs include: conviction that self-care is a faster and more effective method and assessment of one's ailments as trivial.[13] Negative assessment of the effectiveness of the public healthcare system, lack of trust in doctors etc. are among the reasons resulting from failure to meet the expectations of patients.[14–16] Significant reasons for taking up self-care also include the need to aid the conventional treatment of a chronic disease or eliminate the adverse effects of medications prescribed by the physician as well as the need to gain knowledge, diagnose the condition on one's own, and sometimes also the pressure of the environment and susceptibility to the advertisements of medicinal products.

Both in the studies conducted by Mirowska-Guzel et al.[7] and in the studies described by the authors of this paper, the reasons for using self-care among MS patients are consistent – they are aimed at satisfying individual needs, that is "the desire to do something for oneself" or "the desire to alleviate the symptoms of the disease". The following reasons were those resulting from patients' own beliefs: lack of confidence in the effectiveness of conventional treatment vs lack of improvement despite conventional treatment.

According to Scandinavian studies conducted among MS patients, the most popular treatment methods were: acupuncture, nutrition therapy, homeopathy, and spiritual healing.[17] In the study by Mirowska-Guzel et al.,[7] it was indicated that the most commonly used CAM method was herbal medicine. The most popular preparations included: evening primrose seed oil (56%), uncaria tomentosa (the so-called cat's claw; 16%) and Padma (17%). They were followed by the use of vitamin preparations (50%), diet therapy (22%) and massages (34%). Almost every 5th respondent used acupuncture (19%) and bioenergy therapy (19%). More rarely, patients used homeopathy (14%), hypnotherapy (12.5%), reflexology (3%), and yoga (3%). In the study constituting the basis for this paper, the most commonly used methods are dietary supplements and OTC medications, and every 4th respondent uses herbal medicine. The difference between the study conducted by the authors and the study conducted by Mirowska-Guzel et al. results from product classification. In the study conducted by the authors, such preparations as evening primrose seed oil or Padma were assigned to the group of supplements and OTC medications, and in the cited study they were considered to be used in herbal medicine.

Similar results indicating more frequent use of herbal medicine and vitamin preparations were presented in a Canadian study concerning parents of children suffering from cancer. Herbal medicine was the most frequently listed unconventional method used in children, and it was followed by: vitamin preparations, diet therapy, unconventional preparations, homeopathy, and ozone treatment. The most frequent complementary methods were: relaxation and imaging, massage, bioenergy therapy, and hypnosis.[15]

Using cannabis and its derivatives is allowed for treatment in countries such as Canada, the USA (in some states), Czech Republic, or Holland. The Polish medical community, however, does not share the optimistic views regarding the application of the so-called medical marijuana in official MS treatment. Nevertheless, many patients suffering from a chronic disease are willing to do anything possible (even take illegal action) and they use even the treatment methods which are very controversial in order to alleviate the ailments and halt the course of the disease.

Despite the fact that medical marijuana was legalized in Poland on November 1, 2017 and is allowed for sell in Polish pharmacies, using legal treatment remains out of

patients' reach (as of September 20, 2019). Treatment refund is, thus, out of the question, and the assumptions of thelegal regulation are difficult to meet. Cannabis medications are to be prepared by pharmacists on the basis of a prescription issued by a doctor. In Poland, there are few doctors and pharmacists with experience in such therapy. The procedure of implementing cannabis treatment is not easy, and the Ministry of Health received an opinion from the Agency for Health Technology Assessment and Tariff System (Agencji Oceny Technologii Medycznych i Taryfikacji) according to which the effectiveness of marijuana treatment is low.[18,19] In June 2018, the Office for Registration of Medicinal Products, Medical Devices and Biocidal Products (Urząd Rejestracji Produktów Leczniczych, Wyrobów Medycznych i Produktów Biobójczych) received the first offer for the import of dried cannabis from Canada. It has been publicly announced that the application was considered positively and the product is expected to be available at the end of November 2018.

Conclusions

Even though 10 years have passed since the study by Mirowska-Guzel et al.,[7] other studies confirmed that the popularity of self-care remained unchanged. The reasons for and the methods of CAM were also found to be convergent. It probably results from years-long lack of complex care for the patient as well as the lack of effective treatment method, free of adverse effects. Self-care methods used among MS patients in Poland are different than those used in the Scandinavian countries, and are similar to the ones indicated in the study, conducted among the parents of children suffering from cancer.

Lack of representativeness constitutes one of the limitations of the study. Nevertheless, the sample reflects the population of patients, most of whom are women. Due to the lack of probability selection, the decision to abandon statistical reasoning was made. The results and conclusions are, therefore, of illustrative nature and may serve as an inspiration for further research as well as an important rationale, which indicates the necessity to create patient databases.

The use of self-care should be considered as one of the most important ways of satisfying the health needs of patients, in whom a severe, unpredictable disease, which often leads to disability, is suspected or diagnosed. Thanks to the actions taken, patients believe that they are able to "halt" or slow down the disease progress, in order to maintain the function of the organism for as long as possible. Taking independent, "corrective" measures is a way to get rid of the uncertainty, which occurs between the alternating feelings of hope and desperation.[20] These measures constitute somewhat of a safety buffer, which enables patients to retain control of their own lives. Social interactions occurring during the process of seeking information about the ways other patients deal with their illness also constitute an important element of limiting the uncertainty. Learning from the experiences of "significant others" (which is what people suffering from the same condition, members of online patient groups, become) makes it possible to release negative emotions and place oneself in a proper reference group (which no longer consists of healthy people, but of other patients).

In diseases with variable and unpredictable course, in which the states of being healthy and ill (remissions and relapses) intertwine, the use of self-care may be a symptom of "an effort targeted at preparing for the unpredictable",[21] and a display of adaptive strategies in the process of coping with the disease, fear and frustration. Self-care and the search for new solutions is a positive situation, when patients are (still) strong enough to fight their illness. As the disease progresses (subsequent relapses, new symptoms) patients "convert" to conventional medicine, most adequate in crisis situations. At this point, the patient is not a "victim of the disease",[21] but becomes the subject, retaining their freedom despite the circumstances beyond their control. Thanks to the unique experience which has been gained (e.g., the use of cannabis), the patient may continue their "tale of the disease", becoming someone important for other sufferers. This way, they compensate for the decline of the their social status resulting from the limitations brought by the disease. It is also important for the social environment of the ill individual, which can seek for new "solutions" for their companion and remain active as well as involved in relations. Self-care conducted within the patient's social networks also plays an integrative and strengthening function (social support).

People using self-care assessed the out-of-pocket treatments best. It should be remembered, however, that conventional medicine treatments can also be dangerous. If patients take conventional treatments without consulting their physician, there is a risk that the effects of therapy will overlap in a harmful way. Such threats occur in the context of the lack of education and access to reliable information among MS patients.

Worse assessment of MS treatment funded by the National Health Fund (NHF) may be associated with the widespread negative assessment of the access to health services and their quality as well as negligence of non-clinical aspects of the disease (the comfort of life, symptom alleviation, pain, fear of becoming dependent, emotional and spiritual needs of patients). Thus, the best way to improve the negative assessment of state-funded conventional treatment would be to recognize the patient as a participant in the process of treatment and provide them with better access to such treatments as motor rehabilitation, massages or cryotherapy. An important conclusion from the conducted study is also the necessity to broadly educate the patients suffering from chronic diseases who use self-care.

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