Application of complementary and alternative medicine methods in Huntington's disease

Zastosowanie metod medycyny uzupełniającej i alternatywnej w chorobie Huntingtona

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Wprowadzenie. Metody medycyny uzupełniającej i alternatywnej (CAM – complementary or alternative medicine) są często stosowane, ale nigdy nie były szczegółowo analizowane u pacjentów z chorobą Huntingtona (HD – Huntington's disease).

Cel. Scharakteryzowanie stosowania CAM u pacjentów dotkniętych HD.

Materiały i metody. Osoby stosujące CAM wybrano z kohorty pacjentów z chorobą Huntingtona, badanych w poznańskim ośrodku realizującym projekt REGISTRY. Bazując na danych demograficznych populacji polskiej dokonano porównania stosowania CAM przez osoby szukające porady u specjalistów CAM w kohorcie HD oraz w populacji ogólnej. W trakcie analizy wyróżniono takich specjalistów CAM, jak: homeopata, zielarz i inni.

Wyniki. W grupie 57 pacjentów z kohorty HD z poznańskiego ośrodka było 3 pacjentów, którzy byli na wizycie u specjalisty CAM i zastosowali metody CAM. W grupie HD metody CAM były stosowane częściej niż w populacji ogólnej (HD 5,2 vs. populacja ogólna 1,8%). Pacjenci z HD korzystali z porad zielarza, homeopaty i bioenergoterapeuty. Wszyscy pacjenci z HD byli żonatymi mężczyznami, z ukończonym poziomem ISCED-3 (ISCED – International Standard Classification of Education), z objawami ruchowymi HD i wszyscy rozpoczęli stosowanie CAM w roku postawienia diagnozy. Objawy ruchowe, poznawcze, funkcjonalne oraz zaburzenia zachowania u wszystkich 3 pacjentów były nasilone w podobnym stopniu, gdy pacjenci deklarowali korzystanie z CAM podczas wizyty.

Wnioski. Rozpowszechnienie korzystania z porad specjalistów CAM wśród osób z HD wydaje się być większe niż w populacji ogólnej. Moment postawienia diagnozy klinicznej, gdy osoba z zachowanymi zdolnościami poznawczymi staje się świadoma tragicznego końca HD oraz braku możliwości wyleczenia tej choroby, jest czynnikiem spustowym dla zastosowania CAM.

Słowa kluczowe: *medycyna uzupełniająca i alternatywna, choroba Huntingtona, choroba rzadka*

Introduction. Complementary or alternative medicine (CAM) is a common therapeutic approach but it was never analyzed in Huntington's disease (HD) patients.

Aim. The aim of the study was to characterize CAM utilization in individuals affected by HD.

Material & Method. We used an HD cohort from the REGISTRY Study Site of Poznan, Poland to select individuals who utilized CAM methods. Based on demographic data from the Polish population we were able to compare the use of CAM by patients seeking the CAM specialists' advice in an HD cohort and in general population (GP). The analysis was stratified by such CAM specialists as homoeopathist, herbalist and others.

Results. Among 57 representatives of the Poznan Study Site HD cohort we found 3 patients who visited a CAM specialist and utilized CAM methods. Comparing our HD group with Polish GP we found a significantly higher prevalence of CAM utilization in HD cohort (HD 5.2% vs. GP 1.8%). HD patients visited a herbalist, a homoeopathist and a bioenergotherapy specialist. All HD subjects were married men, at the ISCED-3 education level (ISCED; International Standard Classification of Education), with manifested HD motor impairment, who started CAM utilization within a year of clinical diagnosis. Motor, cognitive, functional and behavioral impairments in all three subjects were on a very similar level when CAM utilization was declared at the study visit.

Conclusion. The prevalence of CAM specialists' advice requests in HD-affected individuals seems to be higher than in GP. The trigger for CAM application is the moment of HD clinical diagnosis, when a still cognitively competent patient becomes aware of fatal HD outcome and lack of conventional medicine response for their health needs.

Key words: *complementary and alternative medicine, Huntington's disease, rare disease*

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Introduction

Huntington disease (HD) is a neurodegenerative, progressive, autosomal dominant disorder, caused by a CAG repeat expansion in the *HTT* gene located on the short arm of chromosome 4. HD symptoms are motor abnormalities, cognitive impairment and behavioral disturbances. HD symptoms usually appear between 30 and 50 years of age (range 2-85 years) in both genders, which are equally susceptible to HD. Mean survival time from the symptoms onset until dead lasts for about 21 years. There is no cure for this disease and the outcome of HD is still fatal [1].

A long time of being affected and lack of cure for a disease could be a trigger factor to look for complementary or alternative medicine (CAM). CAM is usually defined as any of various systems of healing or treating a disease (as chiropractic, homeopathy, or faith healing) not included in the traditional medical curricula.

Patients' arguments for CAM utilization were widely investigated in the past and are very different. The predictors of CAM utilization are: higher education; poorer health status; transformational experience that changed the patient's worldview in the past; anxiety; chronic pain; a cultural group like environmentalists, feminists, personal growth psychology; back problems and urinary tract problems [2, 3]. In chronic disorders the predictors of CAM utilization are: longer disease duration, moderate or severe symptoms of disorder, lack of positive response to treatment and higher patient's knowledge of their disorder [4]. Satisfaction with the doctor-patient interaction with benefits of treatment reduces a chance for CAM utilization [5] but opposite results were reported for chronic pain [3]. Fear of unsafety of traditional medicines could be the reason for CAM usage [6]. Patients affected by stroke, arthritis and musculoskeletal disorders seem to by mostly predicted to become CAM utilizers [5]. CAM utilization in HD-affected individuals was never examined before. Monogenetic background of this disorder should be recognized by patients as a limiting factor for CAM application but reduced cognition, long duration of disease, lack of cure and hope [7] that CAM could deliver effective relief for HD can increase CAM utilization.

Aim

To compare prevalence of individuals' advice requests from CAM specialists in HD cohort and in general population (GP).

Material and methods

Investigated HD cohort consisted of REGISTRY study participants from the Polish Study Site located in Poznan. REGISTRY is an European observational multicenter longitudinal study conducted in Poland between 2007-2014 and approved by local Ethical Review Board at the Poznan University of Medical Sciences. Each HD patient who participated in the study was interrogated for contacts with a CAM specialist within the last 12 months. Answers were noted in the Client Services Receipt Inventory form [8]. In a similar way contacts with a CAM specialist were estimated in Polish GP. A pollster of this national study lead by the Central Statistical Office asked similar questions and filled a dedicated survey [9]. In details for both investigated groups a comparison of CAM specialist was stratified by homoeopathist, herbalist, other CAM specialist.

HD onset appears usually in the age of 40 years, therefore to ensure similarity (regarding mean age) of both investigated groups the comparative study consisted of people within the age range of 40-69 years.

For the statistical analysis mean and standard deviation (SD) were calculated. Chi-square (λ^2) and Cochrane&Cox (C) tests were applied to verify statistical hypotheses.

Results

Among 57 representatives of the Poznan Study Site HD cohort we found 3 patients utilizing alternative medicine methods. The detailed characteristics of HD cohort is given in the table I. All 3 patients started looking for a CAM specialist just after the HD diagnosis and visited a CAM specialist within the year of the diagnosis (Table I).

Our GP consisted of 17 826 400 participants among whom 326 600 utilized CAM. Most popular was a herbalist as 121 790 individuals declared this CAM specialist consults, and was followed by a homoeopathist with 48 900 individuals. Group of 204 810 individuals declared the consults of other CAM specialists.

Both cohorts were not significantly different regarding age of examination, therefore both had similar exposure time for CAM use. Mean age of our HD cohort was 52.7 years (SD 7.76) and was not significantly different ($C^0=0.599 < C_{0.05}=1.960$) than mean age of GP – 53.5 years (SD 7.62). Both cohorts consisted of individuals aged from 40 up to 70 years. A significantly higher prevalence of CAM utilization – λ^2 test ($p=0.05$), was found in our HD group than in GP (HD cohort 5.2 vs. GP 1.8%).

Table I. Characteristics of HD patients utilizing CAM
Tabela I. Charakterystyka pacjentów z HD korzystających z CAM

Characteristics /parametry	Patient No 1 /pacjent 1	Patient No 2 /pacjent 2	Patient No 3 /pacjent 3
gender /płeć	male /mężczyzna	male /mężczyzna	male /mężczyzna
education level /poziom wykształcenia	ISCED-3	ISCED-3	ISCED-3
marital status /stan cywilny	married /żonaty	married /żonaty	married /żonaty
domicile /miejsce stałego zamieszkania	little town /małe miasteczko	little town /małe miasteczko	village /wieś
age at HD diagnosis (in years) /wiek rozpoznania HD (w latach)	39	46	65
age at CAM onset (in years) /wiek rozpoczęcia CAM (w latach)	40	45	66
types of CAM specialist /rodzaje specjalistów CAM	bioenergotherapy specialist, herbalist, homoeopathist /bioenergoterapeuta, zielarz, homeopata	herbalist, homoeopathist /zielarz, homeopata	herbalist /zielarz
UHDRS TMS /skala ruchowa UHDRS	35	37	34
TFC /skala funkcjonowania TFC	11	11	12
UHDRS functional scale /skala funkcjonowania UHDRS	23	22	24
UHDRS ind. scale /skala niezależności UHDRS	100%	80%	95%
UHDRS cognitive scale /skala oceny zdolności poznawczych UHDRS	175	181	175
Verbal Fluency test /test fluencji słownej	28	21	28
SDMT /test modalności cyfr-symboli	24	21	24
UHDRS Behavior sc. /skala zachowania UHDRS	5	11	5

Discussion

In this study we intended to evaluate CAM utilization among the HD patients cohort and compare to CAM frequency in GP (in our opinion, it reflects the CAM general prevalence in the Polish population). It is important to note that both REGISTRY study and GP study by the Central Statistical Office were not oriented into direct and insightful interrogation of CAM utilization in the investigated individuals but both contained direct questions about CAM specialists' advice requests. It could also explain lower frequencies of CAM utilization in this study than were noted in other studies [3-6]. Moreover, it is important to note that the questions concerned CAM specialists' advice requests but not simply CAM utilization. CAM is mostly applied without any specialist advice [10-12]. Other factors that could limit CAM utilization in both our investigated cohorts were: the fact that GP consisted of individuals with different health status (healthy, temporarily affected and chronically affected with different disorders), the fact that HD is a genetic disorder with clear background and prognosis, moreover, HD individuals are often cognitively deteriorated loosing ability to look for CAM methods. Extrapolation of this last assumption could be based on the presence of a positive correlation between higher education and higher CAM utilization [2] where a demented patient could be recognized as an equivalent of people on a lower level of cognitive skills but a small study on CAM utilization in Alzheimer disease-affected individuals denies this assumption [13]. Moreover our HD patients started CAM utilization just after diagnosis when they still remained in good general and intellectual condition. Interestingly, chronic disorders when patients are consent of their incurability are not a discouraging factor for patients looking for any alternative treatment options [14].

Genetic background of HD is very clear – a monogenetic disease – and patients often are reconciled with that fact and refer their condition to the *HTT* gene mutation that in their opinion is constant and cannot be changed by currently available methods, both traditional or alternative. Indeed CAM utilization in monogenetic adult disorders is rarely described.

In our HD cohort we found only 3 patients and they utilized altogether 6 CAM methods. It means that patients followed the idea of searching for treatment method by trying them out and were not clearly convinced to use a particular method. It confirms previous studies' results indicating that CAM users usually apply more than one CAM method [15]. Our HD patients were looking for a CAM specialist very early after the diagnosis. They could be classified therefore as the early phase CAM decision-making individuals [16, 17]. Indeed the moment when HD-affected individuals become consent of the diagnosis at HD onset is critical for their way of thinking and often results even in suicidal thoughts and attempts [18].

This study has several limitations beginning from a small number of HD patients entered. It can be explained by the fact that HD is a rare disease. Moreover

the investigated individuals should be interrogated about CAM utilization and not only about the advice by CAM specialists because CAM application usually is not a result of specialists' advice but an individual patient's search for help [19]. The patient's beliefs behind the decision of CAM utilization should be explored. It is however the first study that explores CAM utilization in HD patients and indicates the need of a follow-up study on a European or a global cohort.

Conclusion

1. The prevalence of CAM specialists' advice requests in HD-affected individuals seems to be higher than in GP.
2. The trigger for CAM application is the moment of HD clinical diagnosis, when a still cognitively competent patient becomes aware of fatal HD outcome and lack of conventional medicine response for their health needs.

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