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DEVELOPMENT AND PSYCHOMETRIC PROPERTIES OF A SELF REPORT MEASURE TO ASSESS CLINICIANS' PRACTICES IN SELF MANAGEMENT SUPPORT FOR PATIENTS WITH LONG TERM CONDITIONS.

**JAK PERSONEL MEDYCZNY WSPIERA PACJENTÓW Z CHOROBIAMI PRZEWLEKŁYMI W ICH CODZIENNYM RADZENIU SOBIE Z CHOROBA?
ROZWÓJ I WŁAŚCIWOŚCI PSYCHOMETRYCZNE KWESTIONARIUSZA DLA KADRY MEDYCZNEJ.**

STRESZCZENIE

Koszty opieki nad pacjentami z chorobami przewlekłymi stanowią coraz istotniejszy problem dla służby zdrowia wielu krajów. W związku z tym koncepcja wspierania pacjentów w codziennym radzeniu sobie z chorobami przewlekłymi (self management support) cieszy się rosnącym zainteresowaniem zarówno wśród personelu medycznego i osób zarządzających placówkami medycznymi, jak również naukowców zajmujących się psychologią zdrowia. Codzienne radzenie sobie z chorobą (self management) definiuje się jako: „umiejętność skutecznego radzenia sobie z symptomami choroby, procesem leczenia, jak również z fizjologicznymi i psychologicznymi konsekwencjami oraz zmianami stylu życia związanymi z zapadnięciem na przewle-

klą chorobę”. (Barlow et al, 2002). Powszechnie uznaje się, że efektywne wsparcie pacjentów z chorobami przewlekłymi przez personel medyczny może przyczynić się nie tylko do obniżenia kosztów leczenia chorób przewlekłych, ale również do poprawy zdrowia i jakości życia pacjentów. Jednak, aby personel medyczny mógł skutecznie wspierać pacjentów, musi on posiadać odpowiednie umiejętności, szczególnie w zakresie komunikacji, budowania opartej na szacunku i zaufaniu relacji z pacjentem oraz przekazywania pacjentowi odpowiedzialności za własne zdrowie i wspieranie go w podejmowaniu możliwych do zaakceptowania przez obie strony decyzji w kwestii leczenia.

Prezentowany artykuł opisuje proces projektowania i testowania kwestionariusza do oceny poziomu wsparcia w codziennym radzeniu sobie z chorobą przewlekłą oferowanego pacjentom przez personel medyczny (Practices in Self Management Support - PSMS). Projektowanie i testowanie kwestionariusza obejmowało następujące fazy: przegląd literatury w celu zdefiniowania umiejętności koniecznych do wspierania pacjentów w codziennym radzeniu sobie z chorobami przewlekłymi, przegląd istniejących narzędzi badających umiejętności wspierania pacjentów w codziennym radzeniu sobie z chorobami przewlekłymi, skonstruowanie początkowej listy twierdzeń E. Delphi przeprowadzone w celu wybrania twierdzeń do końcowej wersji kwestionariusza oraz zbieranie danych w celu potwierdzenia struktury czynnikowej i rzetelności narzędzia.

Zbieranie danych zostało przeprowadzone w dwóch fazach. W pierwszej fazie rozesłano kwestionariusz zawierający 40 twierdzeń do 110 osób pracujących z chorymi cierpiącymi na cukrzycę, odmę płucną, depresję i przewlekłe dolegliwości bólowe związane z układem kostnym i mięśniowym. Kwestionariusz wypełniło 90 osób, w przewadze kobiet, ich średni wiek to 44.6 lata. Większość respondentów stanowiły pielęgniarki (32.2%), następnie lekarze (22.2%), paramedycy (12.2%) (np. dietetycy, rehabilitanci) oraz psychologowie (7.8%).

Przeprowadzona analiza czynnikowa pozwoliła na zredukowanie ilości twierdzeń do 25 oraz skonstruowanie trzech podskal: wspieranie pacjentów w codziennym radzeniu sobie z chorobami przewlekłymi – aspekt kliniczny (Clinical Self Management Support) (14 twierdzeń), komunikacja z pacjentem (Patient Centeredness) (4 twierdzenia) oraz organizacja usług medycznych (Organization of Services to Support Self Management) (7 twierdzeń).



Drugą fazę zbierania danych przeprowadzono w celu potwierdzenia struktury czynnikowej i zbadania rzetelności narzędzia. Wersje kwestionariusza zawierającą 25 twierdzeń rozesłano do 1237 osób pracujących z pacjentami z chorobami przewlekłymi i otrzymano 596 odpowiedzi. Podobnie jak w poprzedniej fazie większość respondentów stanowiły kobiety, ich średni wiek to 43.2 lata. Niemal połowa respondentów pracowała jako pielęgniarki (43.6%), następnie, jako lekarze (34.6%), paramedycy (17.6%) i psychologowie (4.2%). Przeprowadzone analizy potwierdziły konstrukcję narzędzia oraz to, że wszystkie podskale charakteryzuje wysoka rzetelność (Cronbach α : 0.94, 0.78 i 0.85).

Wstępne badania potwierdzają, że kwestionariusz PSMS może być stosowany zarówno do ewaluacji programów badawczych, jak i programów mających na celu poprawę jakości usług zdrowotnych.

Acronyms

PSMS – Practices in Self Management Support

SMS – Self Management Support

SM – Self Management

LTC – Long Term Condition

COPD – Chronic Obstructive Pulmonary Disease

INTRODUCTION

The cost and effectiveness of healthcare for LTCs is a growing concern of healthcare systems throughout the world [1]. There is a growing interest in the concept of self management as one of the ways of reducing healthcare costs as well as improving patients' outcomes and quality of life. Self management is defined as "the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition [2]. It is further stated that for self management to be effective, it needs to encompass the "ability to monitor one's condition and to affect the cognitive, behavioral and emotional responses necessary to maintain a satisfactory quality of life".

Effective self management requires patients to be motivated, informed and empowered. At the same time they have to be supported by clinicians who are willing and



skilled to engage in productive interactions, and work in partnership with their patients to develop mutually accepted and followed treatment plans [1, 3, 4, 5, 6]. This means moving away from the traditional approach and changing clinicians' beliefs about their role in promoting self management, followed by learning new practice behaviours and skills.

This article describes developing Practices in Self Management Support (PSMS) a new measure self report measure to assess clinicians' practices in SMS for patients with LTCs. The measure is designed to be used to:

- (1) Assess clinicians' training needs in relation to self management support for LTCs,
- (2) Evaluate the effectiveness of training for clinicians in self management support,
- (3) Assess clinical teams' performance in supporting self management for LTCs,
- (4) Measure self management support provision in quality improvement initiatives in healthcare settings.

METHODS

Phases of PSMS measure development

Phase 1: Literature review

In the first phase in the development process we conducted a literature review to define what skills clinicians need to develop to effectively support patients to self manage their LTC. The literature suggests some practical principles to facilitate patient SM, which include the four behavior change processes [7]: (1) *joint agenda setting*; (2) *problem solving*; (3) *collaborative goal setting* and (4) *goal follow up*. Literature describes other features of effective consultations: (a) encouraging the patient to define their health problems and purpose of consultation; (b) explore options for dealing with these problems; (c) offer the patient choice and respect the choice when it is made; (d) collaboratively set goals and action plans for treatment and maintaining a healthy lifestyle; (e) share the meaning and possible utility of clinical expertise with the patient [8, 9, 10, 11, 12, 13, 14, 15, 16, 17]. It is considered to be important for clinicians' engagement to organize services to enable delivery of care in a way that promotes and encourages patients to self manage [18, 19].

Phase 2: Review of existing measures of SMS practices

The second phase was to review reports that identified measurement of SMS practices (see Table 1). We concluded that none of the measures comprehensively addressed the spectrum of practices to support self management as described above.

Table 1:

Literature review – measures assessing SMS practices, clinicians’ attitudes to patients centeredness and services for self management support

Author	Condition	Target clinicians	Content / coverage	Psychometric properties	Respondent burden	Format	Comments
Bonomi et al (2002) Assessment of Chronic Illness Care (ACIC) [18]	Diabetes, frailty, congestive heart failure asthma, depression	Organizational teams: clinicians, nurses, managers, behavioural scientists	Quality improvement tool to help organizations in evaluating the delivery of care for chronic illnesses in 6 areas: community linkages, self-management support, decision support, delivery system design, information systems, organization of care	Pearson’s correlations between ACIC subscales and faculty ratings ranged from .28 to .52	28 items, rated on four descriptive levels. Within each level respondents choose one of three ratings.	Closed	Validity and reliability not known. Toll was assessed with organizational teams who were taking part in quality improvement collaborations – possible bias.
Brownson et al (2007) The Assessment of Primary Care Resources and Supports for Chronic Disease Self-Management (PCRS) [19]	Developed for diabetes, can be used for any chronic condition	Healthcare staff: clinicians, front-line staff and administrative personnel	Patient support: characteristics of service delivery that enhances self management in the areas of healthy eating, physical activity, emotional health, medication management, management of daily activities and roles. Organizational support: system design in regard to planning, resource	3 pilot studies conducted in four primary care sites. Final assessment with 20 healthcare teams across the US. Cronbach Alphas’ values for individual and organizational support .94 and .90 respectively.	Questionnaire containing 16 items. Statements assessed with ‘grades’ D-A, each grade has a range of 3 numbers	Closed	Size of the sample not known, tool designed to be used for quality improvement



			allocation and evaluation of self management support				
Cockburn et al (1987) 'Attitudes Questionnaire' [20]	General	General practitioners	Doctor's perception of patient care: care vs cure, psychological orientation, continuity of care, mutuality on doctor – patient relationship, preventive medicine, government role	Cronbach's Alpha 0.48-0.67	Questionnaire containing 21 items rated on seven point scale	Closed	Seven sub-scales, low alphas (below 0.70). tested on a small sample
Grol et al (1990) [21]	General	General practitioners	Dimensions: taking patients and their problems seriously, involving patient in decision making, giving information to enable patient take responsibility for his health, feeling responsible for non medical aspects of presented problem	Cronbach Alpha 0.65 (sample of 112 GPs)	Questionnaire, answers on five point Likert scale	Closed	Sensitive to differences between doctors from different countries (UK, Belgium, Netherlands)
Krupat et al (2000) Patient – Practitioner Orientation Scale [22]	General	Primary care physicians	Beliefs about shared decision and the role of patients' expectations	No data	18 items questionnaire, responses on 6-point Likert scale	Closed	No data on tool's psychometric properties available.
Stiggelbout et al (2004) Ideal Patient Autonomy Scale [23]	Aneurysm	Surgeon and surgical residents	Based on 6 moral concepts. Views on paternalistic and consumerist poles of liberal individualist model, Socratic autonomy and ideals of risk disclosure	4 scales, Cronbach's Alphas: 0.83; 0.62; 0.66; 0.63	14 items questionnaire	Closed	Version for physicians and patients available. Tested on small sample (96 patients and 58 physicians). The reliability of three scales is low.

Street et al (2003) [24]	General	Family medicine and internal medicine physicians	Behaviours indicative of physicians' partnership building and active patient participation. Both physicians and patients completed PPOS	Behaviours were coded from audiotapes using system developed by author and colleagues. Reliability of coding system 0.65-0.97	Recorded consultations	N/A	The sample consisted of 20 doctors. Attitudes assessed basing on verbal behavioural measures recorded during consultations.
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Phase 3: Development of the item pool

Based on the literature review and the review of existing measures of SMS we constructed a pool of relevant items. One hundred and fifty-four items were constructed under the following key headings: (1) Individualized assessment of patient's self-management educational needs, (2) Patient self-management education, (3) Collaborative goal setting, (4) Problem solving skills, (5) Emotional health, (6) Patient involvement, (7) Patient social support, (8) Linking to community resources, (9) Agenda setting, (10) Doctor – patient communication (patient centeredness), (11) Follow up, (12) Continuity of care, (13) Coordination of referrals, (14) System for documentation of self-management support services, (15) Patient input to services, (16) Patient care team, (17) Clinician self-awareness, (18) Value of self management, (19) Staff education and training.

Phase 4: E Delphi study

We used E Delphi method to assess relevance of the items to the practice of self management in the UK context [25, 26]. Using online survey we conducted rating of 154 items under categories listed above. E Delphi survey completed by researchers experienced in self management (N=8) included a standard form asking experts to indicate on scale 0-3 ('not at all' to 'very much') how relevant is each item to the practice of self management in the UK context. Items that achieved the highest relevance scores were chosen, leaving a refined pool of 40 items.

Phase 5: Data collection

We invited clinicians who worked with patients with COPD, chronic musculoskeletal pain, diabetes and depression to participate in the study. The study was conducted

as a part of a national UK quality improvement programme known as the Co-Creating Health (CCH) initiative (<http://www.health.org.uk>).

Procedure

Data collection was conducted in two phases. In the first phase (pilot survey) we invited 110 clinicians working with patients with four LTCs to complete the web based questionnaire. Respondents were presented with the list of 40 statements selected in the previous stage describing different SMS practices, and asked to rate how often they apply each in their clinical practice. They responded using a 7-point Likert scale ('not at all' – 'every time I see a patient with LTC' plus 'does not apply' option). We used factor analysis on the data to inform selection of the items for the final measure.

In the second phase (confirmatory study) we recruited 596 clinicians working with patients with the same four LTCs as in the first study, to complete the final version of PSMS measure. Respondents were presented with the list of 25 statements selected from the pilot data analysis describing different SMS practices, and asked to rate how often they apply each in their clinical practice using 7-point Likert scale as described above. We conducted a factor analysis using an oblique rotation solution to confirm the structure of the PSMS sub scales and to establish its internal reliability.

RESULTS

Phase 5 (a): Pilot Study

Demographic characteristics of respondents

Of 110 clinicians invited to complete a pilot version of PSMS measure 90 (82%) completed the entire questionnaire. The majority of respondents were females, mean age 44.6 years, working in clinical roles. Most of respondents were nurses (32.2%), followed by doctors (22.2%), professionals allied to medicine (12.2%) and psychologists (7.8%). 25.6% of respondents did not state their profession. Respondents on average worked in healthcare for 20.8 years and 15.7 years directly with patients with LTCs.

Factor analysis

Factor analysis was conducted using the principal components method. For the final measure we selected items with factor loading $\geq .60$ [27, 28]. Twenty- four items had factor loadings fulfilling this criterion. See Table 1 for these results.

Phase 5 (b): Confirmatory Study

Demographic characteristics of respondents

To confirm the factor structure and test internal consistency of PSMS measure we invited another group of clinicians working with patients with four LTCs (N=1237) to complete the final 25 item web based version of the PSMS questionnaire. We received 596 fully completed surveys (48.2% response rate). The majority of respondents were females, mean age 43.2. Almost a half of the sample was nurses (43.6%), followed by doctors (34.6%), professionals allied to medicine (17.6%) and psychologists (4.2%). Respondents on average worked in healthcare for 18.7 years and 13.4 years directly with patients with LTCs.

Factor analysis and internal reliability

The final factor analysis was conducted on 25 items using an *oblique rotation solution* for three factors. An additional item was added since the measurement of the construct of negotiation of the purpose of the consultation (agenda setting) had inadequate item coverage. See Table 2.

Table 2.
Descriptive statistics and factor loadings for PSMS items

<u>ITEM</u>	MEAN	SD	FACTOR LOADING
Help patients to develop their skills needed for effective self management.	5.8	1.4	.76
Collaborate with patients in setting treatment goals.	6.0	1.4	.67
Help patients in developing individually tailored problem solving skills.	5.7	1.4	.78
Help patients to overcome their fear and anxieties by providing them with what they want to know about their condition.	6.1	1.3	-.43

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Build self management strategies on those that the patient is already successfully applying.	5.8	1.5	.70
Share power and responsibility with the patient.	5.7	1.5	.78
Explore social support resources available for the patient and encourage him/her to use those mostly fitting patient's needs.	5.2	1.7	.75
Discuss with the patient about joining condition related support groups.	5.5	1.6	.82
Establish and maintain a trusting relationship with the patient.	6.3	1.5	.65
Give patient individually tailored explanation of the symptoms, condition and treatment.	6.0	1.5	.63
Actively follow up each patient's goals.	5.1	1.8	.64
Offer support when the patient encounters any problems with maintaining goals.	5.4	1.6	.65
Give the patient a choice about the care team member who will coordinate their care plan.	3.8	2.3	.60
Coordinate referrals by all care team members.	3.8	2.3	.39
Have a self management record included in the patient's documentation that is accessible to all care team members.	4.24	2.5	.64
Regularly ask patients about their opinions regarding service provision and proposed changes.	4.4	1.8	.69
Build a patient care team with professionals who have complementary skills.	4.3	2.2	.64
Spend time on identifying organizational barriers hampering your self management support to patients.	4.1	1.9	.67
Prioritise self management support in your current workload.	4.4	1.8	.15
Regularly train other care team members in self management support.	3.7	2.2	.49
Work on developing and implementing best practice guidelines for patients with long term conditions.	4.7	2.0	.49
Prepare individualized guidelines on medication administration for each patients.	3.8	2.5	.51



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Discuss with each patient potential risks and benefits associated with choosing different treatment options.	5.3	2.0	.60
Explore patient's knowledge of his/her condition to avoid making treatment decisions based on incomplete or wrong information.	5.5	1.8	.50
Allow the treatment to run course to see its true benefits.	5.2	2.0	.69
Identify and select out patients who may not be able to self manage their condition.	4.8	1.9	.48
Reorganise the service to maximize self-care by patients with long term conditions.	3.4	2.1	.40
Ensure that your explanation of the condition, course of treatment and likely outcomes are fully understood by the patient.	5.8	1.3	.33
Talk to the patient about the risk and likely outcomes of his/her condition.	5.8	1.6	.59
Talk to the patient about the limitations of what health service can offer for their condition.	5.1	2.0	.57
Consider healthcare costs of care decisions.	3.8	2.3	.29
Customize treatment recommendations in response to patients' preferences and beliefs.	5.3	1.7	.63
Refer the patient to the professional who can help with his/her psychological problems.	5.2	1.9	.50
Make it easy for the patient to ask questions during the course of the consultation.	6.3	1.1	.47
Ensure that the patient is comfortable with a jointly agreed management plan and decisions	6.2	1.2	.83
Know the patient's cultural and religious background. customs and possible barriers/limitations for treatment that can result from it.	5.3	1.6	.62
Read the patient's documentation before each appointment to recall important information and consider what needs to be	5.8	1.6	.50



talked through.			
Have regular care team meetings to discuss each patient's course of treatment and progress.	3.7	2.2	.63
Undertake joint problem solving to support patients to meet their goals.	5.3	1.8	.74
Jointly agree how and when the patient's progress will be monitored	5.2	2.0	.70

Factorial structure of final PSMS measure

<u>ITEM</u>	<u>FACTORS</u>		
	1	2	3
CLINICAL SELF MANAGEMENT SUPPORT			
Share power and responsibility with the patient.	.73	.32	.52
Helping patients in developing individually tailored problem solving skills.	.85	.35	.33
Helping patients to develop their skills needed for effective self management.	.84	.40	.42
Ensure that the patient is comfortable with a jointly agreed management plan and decisions.	.72	.32	.59
Discuss with the patient about joining condition related support groups.	.66	.40	.22
Collaborate with patients in setting treatment goals.	.84	.41	.52
Build self management strategies on those that the patient is already successfully applying.	.85	.46	.47
Actively follow up each patient's goals.	.86	.50	.46
Offer support when the patient encounters any problems with maintaining goals.	.80	.46	.53
Explore social support resources available for the patient and encourage him/her to use those mostly fitting the patient's needs.	.76	.53	.37
Undertake joint problem solving to support patients to meet their goals.	.87	.47	.50
Establish and maintain a trusting relationship with the patient.	.68	.26	.50
Before the consultation proper negotiate an agreed agenda for the patient's	.60	.52	.37

visit.			
Jointly agree the purpose of consultation.	.64	.44	.46
ORGANISATION OF SERVICES TO SUPPORT SELF MANAGEMENT	1	2	3
Spend time on identifying organisational barriers hampering yourself management support to patients.	.59	.66	.30
Built a patient care team with professionals who have complementary skills	.31	.75	.33
Give the patient a choice about the care team member who will coordinate their care plan.	.31	.75	.32
Jointly agree how and when the patient's progress will be monitored.	.58	.61	.58
Regularly ask patients about their opinions regarding service provision and proposed changes.	.49	.72	.29
Have a self management record included in the patient's documentation that is accessible to all care team members.	.44	.69	.18
PATIENT CENTEREDNESS	1	2	3
Allow the treatment to run its course to see its true benefits.	.51	.40	.72
Discuss with each patient potential risks and benefits associated with choosing different treatment options.	.36	.33	.82
Customise treatment recommendations in response to patients' preferences and beliefs.	.55	.36	.83
Give patients individually tailored explanation of the symptoms.	.41	.28	.82

The resulting measure comprised three subscales:

Clinical Self Management Support covers building an equal doctor-patient relationship, using the four behavior change processes (agenda setting, goal setting, problem solving and follow up) and exploring patient's self management strategies (14 items). These are derived from factor 1.

Patient Centeredness covers customizing the treatment to a patient's preferences and taking an individualized approach (4 items). These are derived from factor 3.

Organisation of Services to Support Self Management covers clinicians' engagement in organising service provision to support SM, building multidisciplinary care teams and supporting patients' involvement in service development (7 items). These are derived from factor 2.

We evaluated the internal consistency of each subscale using Cronbach α . All subscales have very good internal consistency with Cronbach α values: Clinical Self Management Support 0.94; Patient Centeredness 0.81 and Organization of Services to Support Self Management 0.82, and all item-total correlations above 0.50.

DISCUSSION AND CONCLUSIONS

Discussion

Our research has developed the measure - Practices in Self Management Support (PSMS) that is designed to assess clinicians' use of self management support practices for patients with long term conditions. The measure comprises three subscales: Clinical Self Management Support, Patient Centeredness and Organization of Services to Support Self Management. All subscales have very good internal reliability.

There are some limitations that need to be considered when applying the PSMS measure.

To the pilot study we invited clinicians who volunteered to attend a professional training addressing principles and practice of SMS. Respondents were asked to complete the survey before they attended the first workshop to avoid data skewing, however we may suspect that volunteers for the training have already had a particular interest, and possibly relevant experience in supporting self management for LTCs. Although we achieved a very good response rate (82%), almost a quarter of participants did not state their professional role and type of employing organization which further impacts our ability to establish how representative was that sample.

In the second stage of data collection we recruited clinicians working with patients with four LTCs who have not been offered the training programme in SMS. In this study the response rate was significantly lower (48.2%) and the majority of respondents were employed in primary care organizations. We may presume that this sample lacks secondary care consultants who play an important role in supporting patients' self management, and thus its representativeness is also limited.

Conclusion

The measure is comprehensive and covers the areas considered important for providing patients with effective self SMS. It includes items referring to practical principles of facilitate patient self management which include the four behavior change

processes: agenda setting, goal setting, problem solving and follow up [9], as well as other features of effective consultation as described in the literature. The PSMS covers not only the aspects of the clinician -patient relationship and interaction during the clinical consultation, but also refers to the wider organizational context of self management support including clinicians' engagement in organizing the work of the patient care team, service provision, as well as patients' involvement in service changes. In a subsequent study we have shown the PSMS is effective in evaluating the outcomes of training that addresses the principles and practice of self management support [29].

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