

The Challenges of Multimorbidity from the Patient Perspective

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BACKGROUND: Although multiple co-occurring chronic illnesses within the same individual are increasingly common, few studies have examined the challenges of multimorbidity from the patient perspective.

OBJECTIVE: The aim of this study is to examine the self-management learning needs and willingness to see non-physician providers of patients with multimorbidity compared to patients with single chronic illnesses.

DESIGN: This research is designed as a cross-sectional survey.

PARTICIPANTS: Based upon ICD-9 codes, patients from a single VHA healthcare system were stratified into multimorbidity clusters or groups with a single chronic illness from the corresponding cluster. Non-proportional sampling was used to randomly select 720 patients.

MEASUREMENTS: Demographic characteristics, functional status, number of contacts with healthcare providers, components of primary care, self-management learning needs, and willingness to see nonphysician providers.

RESULTS: Four hundred twenty-two patients returned surveys. A higher percentage of multimorbidity patients compared to single morbidity patients were "definitely" willing to learn all 22 self-management skills, of these only 2 were not significant. Compared to patients with single morbidity, a significantly higher percentage of patients with multimorbidity also reported that they were "definitely" willing to see 6 of 11 non-physician healthcare providers.

CONCLUSIONS: Self-management learning needs of multimorbidity patients are extensive, and their preferences are consistent with team-based primary care. Alternative methods of providing support and chronic illness care may be needed to meet the needs of these complex patients.

KEY WORDS: multimorbidity; multiple chronic illness; self-management skills.

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BACKGROUND

Although multiple co-occurring chronic illnesses within the same individual are increasingly common,¹⁻³ research on the effectiveness of interventions and outcomes for these complex patients is scarce.⁴ Even fewer studies have examined the challenges of multimorbidity from the patient perspective. Aside from the geriatric literature, exploration of patient-identified needs, barriers to self-care, coping skills, and treatment preferences have largely been disease-specific. A few recent qualitative studies have described barriers to self-management and coping strategies in relatively small samples of patients with multiple chronic illnesses.⁵⁻⁷ To more systematically assess a broader range of topics, we used mixed methods to identify the challenges of multimorbidity experienced by primary care patients served by the Veterans Health Administration (VHA).

The VHA is an ideal setting to explore chronic illness complexity because multimorbidity is highly prevalent among veterans.⁸ To initially identify the concerns and preferences of these complex patients, we conducted focus groups with 60 patients having 2 or more chronic illnesses at 8 geographically dispersed VHA primary care clinics.⁹ Not surprisingly, patients identified a number of negative impacts from multimorbidity, including polypharmacy, juggling multiple appointments, poor continuity of care, and difficulty accessing nonscheduled, urgent care. Problematic interactions with physicians were also mentioned, often in relation to specialty care, and included incidents in which providers had ignored concerns or provided conflicting advice. Most participants expressed overall satisfaction with their primary care physicians but were also appreciative of nonphysician providers.⁹ Lack of time and motivation interfered with self-management regimens, but knowledge and skills deficits were noted as contributing factors. Although this qualitative work provided important insights about the burdens of multimorbidity and its impact on health care, the extent to which these concerns differed from patients with a single chronic illness was not clear.

OBJECTIVE

The present study used a cross-sectional survey to compare the self-management learning needs of primary care patients with multiple chronic illnesses and patients with single chronic illnesses. Although we hypothesized that significantly more patients with multimorbidity would be willing to learn

Table 1. Chronic Illnesses Used to Form Multimorbidity and Single Morbidity Groups

	Multimorbidity	Single Morbidity
Metabolic	Hypertension, Hyperlipidemia, Diabetes, AND Ischemic Heart Disease (patients required to have at least 3 of the 4 diseases)	Hypertension OR Hyperlipidemia OR Diabetes OR Ischemic Heart Disease ONLY
Obesity	Obesity, Osteoarthritis, Low back pain, GERD, AND Benign Prostatic Hyperplasia (patients required to have at least 3 of the 5 diseases)	Obesity OR osteoarthritis OR low back pain OR GERD OR Benign Prostatic Hyperplasia ONLY
Psychiatric	Depression, PTSD, Other Anxiety Disorder, Alcohol Abuse, Substance Abuse, Bipolar Disorder, Schizophrenia (patients required to have at least 4 of the 7 diseases)	Depression OR PTSD OR Other Anxiety Disorder, OR Alcohol Abuse OR Substance Abuse OR Bipolar Disorder OR Schizophrenia ONLY

various self-management skills than patients with single morbidity, we were uncertain whether this would only be true for certain types of skills. Assuming that nonphysician health-care providers play an important role in providing skills training and other support services, we also compared multimorbidity and single morbidity patients' willingness to see different types of nonphysician providers. We hypothesized that multimorbidity patients would be more willing to see nonphysicians, but were unsure whether this would be true for only certain types of providers.

PARTICIPANTS

We developed a sample from primary care patients served by a Veterans Affairs Medical Center and its affiliated outpatient clinics in South Texas. Eligible patients had at least one primary care clinic encounter during the previous 13 months. For patients meeting visit eligibility criteria ($N=23,068$), we extracted all primary and secondary encounter diagnoses, both inpatient and outpatient, for the previous 3 years from the VHA's electronic medical record system.

Using ICD-9 codes, the presence or absence of 45 diagnoses groups representing prevalent chronic illnesses in the veteran population was coded for each patient.¹⁰ The patients were then stratified into 3 multimorbidity clusters previously demonstrated to be the most highly prevalent among veterans¹⁰ and 3 patient groups with a single chronic illness from the corresponding cluster for a total of 6 separate groups (Table 1). The multimorbidity clusters were identified from a prior analysis using an agglomerative hierarchical clustering technique on the encounter diagnoses of 1.645 million primary care patients served by the VHA during a 4-year period (1997–2001).¹⁰ Although patients in the multimorbidity clusters could have other chronic diseases *in addition* to the diseases within their cluster, they could not have any of the diseases from the other 2 multimorbidity clusters. Patients in the single disease groups had only 1 of the 45 chronic illness diagnosis groups. We then used nonproportional sampling to randomly select 120 patients from each group for a total of 720 patients.

MEASUREMENTS AND DATA COLLECTION

Our mailed survey assessed demographic characteristics and functional status using the physical and mental component scores of the SF-12V.¹¹ We also asked patients to report the number of times they had seen their primary care physician and any specialist physicians in the last 12 months, and whether the health care they had received was obtained from the VA only or from both VA and nonVA sources.

The 20-item Components of Primary Care Instrument (CPCI) was included to assess patients' perception of the delivery of 4 components or "attributes" of primary care services thought to be associated with quality of care: patient preference for their primary care physician, interpersonal communication with their primary care physician, the physician's accumulated knowledge of the patient, and coordination of care by the primary care physician.¹² Each item consists of a stem with a Likert-type response on a 1-to-5 scale anchored by "strongly disagree" and "strongly agree." Scale items are averaged with the score of 5 indicating the highest level of perceived delivery of the primary care component. CPCI ratings have been found to be associated with the delivery of preventive screenings and health habit counseling.¹³

We also constructed a 22-item scale to measure the extent to which patients were willing to learn self-management skills. The goal was to create a measure to assess patient-identified learning needs for individuals with multiple chronic illnesses as opposed to typical needs assessments that are disease-specific (e.g., cancer) or setting-specific (e.g., inpatient). The scale reflected 12 "common tasks" for chronic illness previously identified through a literature review¹⁴ and 10 others identified through our earlier focus groups of veterans with multimorbidity.⁹ The scale uses a 5-point rating scale indicating patients' desire to learn each self-management skill (4 = would definitely want to learn, 3 = would probably want to learn, 2 = would consider learning, 1 = would probably not want to learn, and 0 = would definitely not want to learn). Cronbach's alpha was 0.94, indicating good internal consistency. Principal component factor analysis with a promax rotation was used to examine construct validity and indicated that a 1-factor solution provided the best fit for the data.

We also included items assessing patients' willingness to receive care from 11 types of nonphysician healthcare professionals to help their primary care physician "to monitor their progress, teach self-management skills, or help them cope with their illness." Respondents rated their willingness to see each nonphysician on a 5-point scale (4 = would definitely see to 0 = would definitely not see). Because willingness to see a specific type of healthcare provider might be influenced by prior experience with that provider type, we also assessed whether or not participants had actually received care from each type of nonphysician in the past 6 months.

A survey containing the instruments described above was mailed to each eligible subject using a modification of Dillman's total design methodology.¹⁵ This approach uses a series of carefully spaced mailings to establish trust and reduce respondent burden, including a pre-notification letter, survey packet with return envelope, reminder postcard, and second survey packet to nonrespondents. Individuals not responding to the second mailed survey were contacted by phone to verify their address and offered a US \$10.00 incentive to return the survey. The study was approved by our institutional review board.

Table 2. Comparisons of Single Morbidity and Multimorbidity Patients

	Single morbidity, N=195	Multimorbidity, N=227	p Value
Males %	73	90	<0.001
Median age	50	57	<0.001
European American %	55	59	0.42
Received VA care only (%)	41	57	0.002
Saw PCP >4 times in past 12 months (%)	11.4	33.3	<0.001
Saw specialist physician >1 time in past 12 months (%)	32.4	53.9	<0.001
Mean PCS 12V (SD)*	39.5 (7.1)	34.8 (7.4)	<0.001
Mean MCS-12V (SD)*	42.8 (10.3)	38.6 (12.1)	<0.001
Mean components of primary care subscale scores (SD) [†]			
Coordination of care	3.0	3.3	0.02
Communication	3.8	3.8	0.18
Preference for usual provider	3.7	4.0	<0.001
Accumulated knowledge	3.0	3.3	<0.001
Mean self-management learning skills score (SD) [‡]	9.7 (7.7)	12.7 (7.2)	<0.001
Mean willingness to see nonphysician providers score (SD) [§]	3.4 (4.0)	4.5 (4.2)	0.01

*Higher scores indicate higher functioning

[†]Higher scores indicate more positive experiences

[‡]Scores indicate number of skills patients were "definitely willing" to learn

[§]Scores indicate number of nonphysician provider types patients were "definitely willing" to see

ANALYSIS

We originally planned to compare the 6 groups on the various measures of interest. Tests of homogeneity of covariance matrices, however, found significant variance-covariance heterogeneity between groups, which is a violation of an underlying assumption of linear discriminant function analysis. When the 3 multimorbidity groups and the 3 single morbidity groups were combined, the variance-covariance matrices were found to be equivalent. We then compared the combined single morbidity group and the combined multimorbidity group on sociodemographic characteristics, functional status, primary care attribute scores, and other measures using χ^2 on categorical variables and a nonparametric method (Wilcoxon test) on continuous measures that had nonnormal distributions. To facilitate ease of interpretation on the group comparisons, the 5-point ratings of "willingness to learn" the 22 self-management skills and "willingness" to see the 11 nonphysician providers were dichotomized such that only ratings of "definitely willing" were conservatively coded as "yes" and all other responses were coded as "no." Missing responses on these scales were also coded as "no". The number of "definitely willing" responses for each scale was summed to yield a total self-management learning needs score (ranging from 0-22) and a total willingness to see nonphysician providers score (ranging from 0-11). Spearman correlation coefficients were used to examine the association between total self-management learning needs scores, total willingness to see nonphysician provider scores, and the CPCI subscale scores.

RESULTS

Of the 720 mailed surveys, 422 were returned. Twenty patients (2.7%) were subsequently found to have moved with no forwarding address or to have died, yielding an overall adjusted return rate of 60%. Multimorbidity patients were more likely to have returned surveys than those with a single chronic illness (64 versus 56%; $\chi^2=5.28$; $p=0.02$). As expected, patients in the multimorbidity groups were significantly older, more likely to be male, and had poorer functional status (Table 2). Significantly more multimorbidity subjects reported having received their health care from the VA only and seeing their primary care physician more than 4 times and their specialist physicians more than 1 time in the past year. They also rated their experiences on 3 of the 4 primary care attributes significantly more positive than the single morbidity patients.

On average, the total number of 22 self-management skills that multimorbidity patients "definitely" were willing to learn was significantly higher than the total number endorsed by single morbidity patients. Examination of the individual self-management skills indicated that a higher percentage of multimorbidity patients compared to single morbidity patients were "definitely" willing to learn all 22 self-management skills; of these, only 2 were not significant ("meet responsibilities at home" and "reduce alcohol intake"; Table 3). There were interesting differences in the rank order of items endorsed by the 2 groups. For example, among multimorbidity patients, the

Table 3. Percent of Single Morbidity Versus Multimorbidity Patients "Definitely" Willing to Learn 22 Self-Management Skills

Self-management skill	Single morbidity, N=195%	Multimorbidity, N=227%	p Value
Monitor important symptoms	51.3	69.6	<0.001
Use medications correctly	56.9	74.9	<0.001
Manage medical emergencies	56.4	67.4	0.02
Eat healthy diet	53.9	65.6	0.01
Lose weight	44.6	62.1	<0.001
Exercise or stay physically active	52.8	63.0	0.03
Reduce stress	59.0	68.3	0.047
Talk to and question physician	48.2	66.5	<0.001
Identify or use resources in community	37.4	48.0	0.03
Meet responsibilities at work or home	46.2	54.6	0.08
Adjust to physical limits	46.2	63.0	<0.001
Get support from family or friends	40.5	51.5	0.02
Manage emotional reactions	45.6	62.1	<0.001
Identify or use hospital resources	55.4	66.5	0.02
Handle finances or benefits	44.1	55.1	0.02
Manage pain	51.3	69.2	<0.001
Improve sleep	55.9	69.6	0.004
Develop hobbies or leisure activities	34.4	52.0	<0.001
Improve sexual relationship	40.0	56.4	<0.001
Take care of spiritual or religious needs	33.9	48.5	0.002
Stop smoking	8.7	23.4	<0.001
Reduce alcohol intake	8.7	12.8	0.18

5 skills endorsed by the greatest percentage of patients were: use medications correctly, monitor important symptoms, improve sleep, manage pain, and reduce stress. The 5 skills endorsed by the greatest percentage of single morbidity patients were reduce stress, use medications correctly, manage medical emergencies, improve sleep, and identify or use hospital resources.

Compared to single morbidity patients, a significantly higher percentage of multimorbidity patients reported that they were "definitely" willing to see 6 of the 11 types of nonphysician healthcare providers to support their care: physician's assistant, psychologist, social worker, nutritionist, pharmacist, and "any health professional who works closely with and communicates with my doctor." A significantly higher percentage of multimorbidity patients compared to single morbidity patients also reported having received care from 6 of the 10 nonphysicians in the past 6 months: nurse, physician's assistant, psychologist, social worker, nutritionist, and pharmacist (Table 4).

Spearman correlation coefficients indicated that total self-management learning needs scores were positively associated ($p < 0.0001$) with total scores of willingness to see the nonphysician providers. This suggests that as patients' willingness to learn self-management skills increased, so did their willingness to see nonphysicians. Furthermore, patients' willingness to learn self-management skills appeared to be strongly associated with their experiences of 3 of the 4 components of primary care: coordination of care ($p = 0.0466$), preference for usual provider ($p = 0.0022$), and accumulated knowledge of the provider ($p = 0.0115$), but not communication ($p = 0.8760$).

CONCLUSIONS

These results suggest that the self-management learning needs of veterans with multimorbidity are more extensive than those of patients with single chronic illnesses. Disease-specific skills such as blood glucose monitoring for diabetes or inhaler use for asthma are important aspects of chronic care, but the "generic" self-management skills assessed in our survey are relevant to most chronic illnesses. Although standardized group

classes such as Lorig's Chronic Disease Self-Management Program can be an efficient method to teach generic self-management skills,¹⁴ they may not adequately address all of the concerns of complex patients with multimorbidity. Of the 20 self-management skills endorsed by a significantly higher percentage of multimorbidity patients, several (e.g., improving sexual relationships) are not included among the topics covered in Lorig's program.¹⁴ This underscores the importance of the collaborative exploration of patient-identified problems and the development of individualized treatment plans.

Although the number of self-management skills endorsed by multimorbidity patients is quite large, it is not our intent to suggest that patients want to, or should even try to, learn 20 self-management skills at once. Indeed, recent research suggests that patients should focus on 1 behavior change at a time.¹⁶ It is our hope instead that primary care providers will be more cognizant of the broad range of needs and help patients prioritize skills training. Complex patients and their physicians, however, may disagree about which problems are most important to target.⁹ Selecting the wrong target or initiating too many changes at once may overwhelm patients and lead to poor adherence.^{16,17} Ideally, targets should be selected on the basis of importance, patient motivation, and readiness for change.

Significantly more multimorbidity patients also reported a greater willingness to see 6 of 11 different types of nonphysician professionals to support their care, teach self-management skills, and provide follow-up monitoring. Furthermore, the willingness to see all 11 types of nonphysicians was significantly associated with patients' self-management learning needs, although multimorbidity patients gave significantly better ratings on 3 of the 4 care components they received from their primary care physicians (PCP). The finding that multimorbidity patients gave higher ratings of their providers in terms of coordination of care, preference for usual provider, and accumulated knowledge is interesting, given that other studies suggest that chronic disease patients are usually less satisfied with their care.¹⁸ The CPCI appears to measure constructs that are independent from patient satisfaction.¹⁹ This may be because, in part, of the fact that their frames of reference differ. Most satisfaction scales ask patients to rate a single visit or overall

Table 4. Percentage of Single Morbidity Versus Multimorbidity Patients Endorsing "Definitely" Willing to See 11 Different Types of Nonphysician Providers and Percentage Who Actually Saw Providers in Past 6 Months

Healthcare provider type	% Definitely willing to see provider			% Actually saw provider in past 6 months		
	Single morbidity, N=195	Multimorbidity, N=227	p Value	Single morbidity, N=195	Multimorbidity, N=227	p Value
Nurse	41.5	49.8	0.09	29.2	42.3	0.005
Physician's assistant	36.4	47.6	0.02	17.4	33.0	<0.001
Psychologist	28.2	45.8	<0.001	11.3	27.8	<0.001
Social worker	22.6	33.9	0.01	5.6	15.9	<0.001
Nutritionist	32.3	45.8	0.005	5.6	24.7	<0.001
Pharmacist	28.7	43.2	0.002	13.9	27.8	<0.001
Physical therapist	37.4	44.1	0.17	9.2	14.1	0.12
Health educator	32.3	39.2	0.14	4.1	8.8	0.0527
Chaplain	21.5	23.4	0.68	3.6	5.3	0.40
Peer counselor	22.1	28.2	0.15	9.7	11.9	0.48
Any health professional who works closely with and communicates with my doctor	32.3	48.9	<0.001	NA	NA	NA

care, whereas the CPCI refers to experiences with a single physician.¹⁹ The results suggest that multimorbidity patients may understand that their PCPs often do not have the time to teach self-management skills or to check on patients' progress between scheduled appointments. It is also possible that quality interactions with their PCP increased patients' trust to see other providers.

It is important to note, however, that a significantly higher percentage of multimorbidity patients actually received care from 6 of the 11 types of nonphysicians in the last 6 months. Although it is possible that willingness to see nonphysician providers was associated with prior exposure, the percentages of patients who were definitely willing to see nonphysicians greatly exceeded the percentage of patients who *had actually seen* the same provider types by up to 30%. While this suggests that patients desire to have more contact with nonphysicians than they currently do, at some point, multiple appointments might become burdensome. We did not assess how many different providers patients would find acceptable to receive care from at once, but presumably care from non-physicians should also be prioritized to patient needs.

The finding that multimorbidity patients are willing to receive care from nonphysicians such as pharmacists is consistent with our earlier focus groups, which indicated that multimorbidity patients were very willing to work with non-physicians as long as the care supplemented, but not eliminated, physician care.⁹ This is underscored by the fact that almost 50% of multimorbidity patients (versus 32% of single morbidity patients) were definitely willing to receive care from "any healthcare provider who works closely with and communicates with" their PCP. It is increasingly recognized that physicians need not, and should not, be the sole healthcare provider in primary care.²⁰ Although multimorbidity patients appear willing to accept "team-based" care, they definitely want their PCP to be the team "leader."

The present study is limited by the self-report nature of the data, which may not reflect actual behavior. Moreover, our sample was derived from 1 healthcare system, making it difficult to generalize these results to other populations because VHA patients tend to be older, male, and to have more comorbid conditions.^{21,22} Unlike many studies that rely upon samples of convenience, however, the participants in the present study were randomly selected based upon encounter diagnoses representing specific "clusters" of multiple chronic illnesses. Although it is possible that the likelihood of being classified with multimorbidity based upon ICD-9 coding is confounded with increased healthcare contacts, our focus was on recognized chronic illness, not just symptom complaints. Furthermore, the significant differences in SF-12V scores increase our confidence that the multimorbidity group had significantly greater morbidity. We have no reason to believe that our findings of multimorbidity patients' willingness to learn self-management skills will not be true of other patients with multimorbidity, but we hope that others will replicate our work in different populations in different healthcare systems.

Despite the extent of multimorbidity in its patient population, the VHA has demonstrated continued improvements in quality and patient-reported satisfaction.^{23,24} Although these gains are largely attributed to the VHA's implementation of performance measurement and comprehensive electronic medical record, the VHA also transformed its care in the 1990s by shifting emphasis from the inpatient to the outpa-

tient setting and assigning every patient a PCP. As the largest integrated healthcare system in the USA, the VHA also employs a large contingent of interdisciplinary, allied health-care providers. The self-reported needs and preferences of patients with multimorbidity suggest that the integration of team-based care within primary care may help address the challenges of these complex patients.

Currently, however, two thirds of PCP work in autonomous solo or small group practices with limited support staff or capacity to provide skills training and proactive follow-up.²⁵ Failure of third-party payers to reimburse these crucial components of chronic illness care is a contributing factor to the relative lack of this support in most primary care settings.¹⁷ Increasingly, resources for patient self-management support are available from government and not-for-profit foundation Web sites such as National Institutes of Health and the American Diabetes Association. Ultimately, new models of delivering comprehensive chronic illness care such as group clinics, automated telephone disease management programs, or home visits by physician extenders may help to expand these services to patients who need them.

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Conflict of Interest: *None of the authors have any known conflicts that either could directly or indirectly, purposefully or inadvertently affect the conduct, outcome, or reporting of this research.*

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