Grant Final Report
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An Electronic Personal Health Record for Mental Health Consumers

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Abstract

Purpose/Scope: Develop and disseminate health IT evidence and evidence-based tools to support patient-centered care, the coordination of care across transitions in care settings, and the use of electronic exchange of health information to improve quality of care.

Methods: A series of focus groups was used to adapt an existing personal health record for persons with serious mental illnesses. The intervention was tested using a randomized study design (n=170) comparing those using the adapted personal health record to usual care. Participants in the intervention group receive 1. Structured computer assessment and training 2. Help in entering and maintaining the record 3. Health education and coaching centered on principles of patient activation.

Evaluations were conducted at baseline, 6 months, and 12 months through interviews and medical and psychiatric chart review. Outcomes of the study are patient activation, quality of medical care, coordination of medical care, service use, and health status.

Results: Data analysis is currently underway. Preliminary analyses indicate a doubling of receipt of preventive services in the PHR versus usual care groups (39% versus 18%, p=0.001).

Key Words: mental health; chronic medical condition; electronic personal health record

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Final Report

Purpose

Aim 1: To Develop a Mental Health Personal Health Record (MH-PHR) for Mental Health Consumers (6 months). Qualitative methods will be used to incorporate input from mental health consumers, providers, and primary care providers to adapt the Shared Care Plan to the specific needs of persons with mental disorders and one or more chronic comorbid medical condition. Content will be modified and electronic enhancements made to the program based on this information.

Aim 2: To Evaluate, Using a Randomized Controlled Study Design, the MH-PHR (24 months). A 12-month randomized trial (n=150) will be conducted to assess the impact of the MH-PHR on quality of care for persons with serious mental illness and one or more comorbid medical condition. During the first six months of the intervention phase, a clinical care specialist will help the subject complete and maintain a web-based MH-PHR; during the second six months, the subject will continue to have access to the MH-PHR without other clinical support. An attention-control group will receive educational materials about health and self management. Evaluations will be conducted at baseline and every six months throughout the 12-month study.

Scope

Persons with Serious Mental Illness are a highly vulnerable population due to their elevated rates of medical comorbidity, and the poor quality of both their medical and mental health care.[1] A literature extending back more than 70 years has demonstrated the detrimental effect of these illnesses on mortality in persons with serious mental disorders.[2] Standardized mortality ratios for medical deaths (i.e. excluding suicides and accidental deaths) are between 1.5 and 3 times the rate of persons without mental disorders. [3, 4]

Personal Health Records (PHRs) may hold particular promise of linking together disparate sources of care and improving quality for vulnerable populations in fragmented and underresourced public sector settings.[5] The Markle Foundation has defined a personal health record as “An electronic application through which individuals can access, manage, and share their health information, and that of others for whom they are authorized, in a private, secure, and confidential environment.”[6] (p. 14) They describe six key features of the PHR: 1) Each person controls his or her own PHR. Individual PHR users decide which parts of their PHR can be accessed, by whom, and for how long. 2) PHRs contrain information from one’s entire lifetime and all health providers. In contrast to many electronic medical records that often only contain episodic and illness-related information, PHRs contain an ongoing, longitudinal, and lifelong record of information that bridges multiple providers and both illness and wellness. 3) PHRs are accessible from any place at any time. 4) PHRs are private and secure. 5) PHRs are transparent. 6) PHRs permit easy exchange of information across the health system. The report draws a distinction between Personal Health Records and Electronic Medical Records which are

controlled and managed by the health provider or institution, and typically do not span multiple providers. [5]

Methods

The project comprised two phases. In the first phase (6 months), a series of focus groups were conducted with mental health consumers, mental health providers, and primary care providers to adapt the Shared Care Plan to the specific needs of persons with mental disorders. In the second phase (24 months), a randomized trial (n=170) will be conducted to assess the impact of the MH-PHR on quality of care over a 12-month period. During the first six months of the second phase, a Clinical Care Specialist worked with subjects to complete and maintain the PHR; during the final six months, patients continued to have access to the MH-PHR without the clinical care specialist. An attention-control group received a booklet addressing general issues about health and self-management.

Results

Baseline Characteristics

Table 1. Baseline characteristics

Variable	Case (n=85)	Control (n=85)	p-value
Age	49.3 ± 7.14 (85)	49.3 ± 8.11 (85)	0.9840
Male gender	43 (50.6)	41 (48.2)	0.7590
White	13 (15.3)	8 (9.41)	0.2438
Black	68 (80)	74 (87.1)	0.2147
Hispanic ethnicity		2 (2.35)	0.1549
Single	45 (54.2)	38 (44.7)	0.2177
Stable Housing	66 (79.5)	71 (83.5)	0.5028
Stable Job	41 (49.4)	52 (61.2)	0.1247
Disability	23 (27.1)	26 (30.6)	0.6115
income	555 ± 379 (83)	608 ± 449 (85)	0.4088
Medical comorbidities	2.44 ± 1.46 (80)	2.27 ± 1.22 (82)	0.4232
Mental illness	81 (95.3)	81 (95.3)	1.0000
Schizophrenia	21 (24.7)	26 (30.6)	0.3912
Bipolar	14 (16.5)	6 (7.06)	0.0569
Depression	40 (47.1)	41 (48.2)	0.8780
Substance	2 (2.35)	7 (8.24)	0.0868
Other mental illness	4 (4.71)	1 (1.18)	0.1733

Quality of Preventive Services

Table 2. Quality of Preventive Services

Variable	Wave	Case (n=85)	Control (n=85)	p-value
Physical Exam	Baseline	0.54 ± 0.17 (85)	0.55 ± 0.16 (85)	0.6776
Physical Exam	12-Month	0.55 ± 0.15 (85)	0.45 ± 0.25 (85)	0.0033
Screen	Baseline	0.30 ± 0.15 (85)	0.34 ± 0.18 (85)	0.0967
Screen	12-Month	0.21 ± 0.16 (85)	0.19 ± 0.18 (85)	0.4350
Vaccination	Baseline	0.08 ± 0.12 (85)	0.07 ± 0.12 (85)	0.5228
Vaccination	12-Month	0.19 ± 0.20 (85)	0.04 ± 0.08 (85)	<0.0001
Education	Baseline	0.23 ± 0.11 (85)	0.23 ± 0.12 (85)	0.8692
Education	12-Month	0.71 ± 0.30 (85)	0.18 ± 0.10 (84)	<0.0001
Preventives for Woman	Baseline	0.34 ± 0.38 (42)	0.25 ± 0.24 (44)	0.1583
Preventives for Woman	12-Month	0.28 ± 0.27 (42)	0.17 ± 0.26 (44)	0.0543
Preventives for Man	Baseline	0.16 ± 0.28 (43)	0.15 ± 0.26 (41)	0.7809
Preventives for Man	12-Month	0.10 ± 0.23 (43)	0.07 ± 0.18 (41)	0.4908
Total Preventives	Baseline	0.26 ± 0.10 (85)	0.26 ± 0.09 (85)	0.7126
Total Preventives	12-Month	0.39 ± 0.13 (85)	0.18 ± 0.10 (85)	0.0011

References

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List of Publications and Products

von Esenwein, SA. “Recruiting for an IT Study in Safety-net Mental Health Center.” Presentation given for the Agency for Healthcare Research and Quality National Resource Center for Health IT as part of the "Patient Recruitment: Challenges, Trends and Best Practices” webinar. April, 2010.

von Esenwein, SA. and Glick, G. “An Electronic Personal Health Record for Mental Health Consumers.” Poster presented at the AHRQ Health IT 2010 Meeting, Washington D.C., September, 2010.

von Esenwein, SA. “Engaging the public sector patient in their healthcare.” Presentation given for the Agency for Healthcare Research and Quality National Resource Center for Health IT as part of the “Putting the Patient Back in Patient Centered Care” webinar. March, 2011.

von Esenwein, SA. “Changing the way consumers manage their physical, mental health, and substance abuse treatment information.” Presentation given at the 14th Annual ICSI/IHI Colloquium on Health Care Transformation. May, 2011.

von Esenwein, SA. “Changing the Paradigm: How Technology Can Empower the Healthcare Consumer.” Presentation given at the Knowledge Network Summit. September, 2012

Project - Generated Resources:

A Computer Literacy Assessment and Education Manual were created for this study.