

Values-Based Interventions in Patient Engagement for Those with Complex Needs

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Abstract

The objective was to evaluate a novel intervention that integrates a psychological, values-based approach with coordinated care management. This paper describes an integrated comprehensive health record system to enhance engagement with a subset of those with complex needs; those who are high-needs, high-cost (HNHC). Patients are selected after conducting data analysis on the most costly and complex patients of a payer system that works with HNHC patients. Specifically, the Patient Care Intervention Center in Houston TX, applies the values-based intervention to HNHC patients. This pilot study reports data from 18 HNHC patients over 6 months; specifically, outcomes related to daily functioning, depression, working alliance, stages of change, and overall well-being. Additionally, this paper reports preliminary findings from qualitative monitoring of provider experiences implementing the values-based approach and integrated evaluation. HNHC patients improved their daily functioning over 4 months but no other significant changes were found over time. Patients self-reported mild depression, strong working alliances with their provider, being in the contemplation phase of change, and moderate well-being. There also was variation when patients completed the assessments and data points were collected. Although this is a small sample and short time frame, preliminary results suggest that the intervention has a positive impact on HNHC patient daily functioning. Provider accounts of the implementation describe using the evaluation items to inform their interactions with patients, and also suggest that patient literacy level impacts when data can be collected. Other changes to the approach are suggested.

Keywords: values-based intervention, complex needs, high needs-high cost, care coordination

Introduction

COMPLEX NEEDS PATIENTS include those individuals who have chronic medical problems in addition to acute social needs. Such patients may suffer from serious and enduring mental health problems, substance use disorders, and other chronic health problems, in addition to homelessness.¹ Some complex needs patients do not utilize primary or tertiary care while others are frequent utilizers of emergent and tertiary care. Both groups are served poorly, irrespective of their usage of medical services, and tend to have high mortality rates.²⁻⁴

Further, a subgroup of those with complex needs are known as high-need, high-cost (HNHC) patients.⁵ This group has high needs as they “often have multiple chronic conditions, complex psychosocial needs and limited ability

to perform activities of daily living.”⁶ Additionally, they engage with the health system in a high-cost manner; for example, in 2015, Centers for Medicare & Medicaid Services⁵ data showed that in Harris County, 6000 HNHC patients incurred more than \$1 billion in health care costs. HNHC patients’ complex needs are caused by the interplay between profound biopsychosocial needs and a health system that is unresponsive and unaccommodating. For the purposes of this paper, HNHC patients are defined as those who have 2 or more comorbid chronic conditions along with 1 or more social, mental, and behavioral needs (in addition to multiple emergency department visits for unmanaged chronic conditions) and cost the system more than \$130,000 per year. Work by the National Academy of Medicine⁷ describes the essential directions in which health care in the United States needs to change in order to serve the population

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better. Of particular note are a number of the recommended action priorities around: (1) delivering more effective health care and demonstrating this through good quality, innovative outcomes and incentive mechanisms, which drive this; (2) empowering people through linking care and personal context; (3) activating communities; and (4) accelerating the use of real-world data.

As HNHC patients suffer from multiple conditions, they visit different social and medical agencies for their needs. Because agencies work independently, there is no collective record of activity across each organization. The care from each agency is unknown to the other. As a result, there are gaps and overlaps in services, resulting in higher cost and insufficient care. Additionally, HNHC patients are difficult to engage in long-term treatment.⁸ To effectively engage with those who are HNHC, providers need to adapt. Engagement strategies with this group must be altered in order to keep them engaged and to have a longer term impact while providing health interventions. One intervention provides case series evidence for a family-based intervention together with case management designed to increase connectedness across the services in which young people were involved.⁹ Increased coordination across agencies may aid in a reduction of cost and enhance patient engagement by building a single-record system that works and advocates for the patients, instead of each agency dealing with their own independent problem-based accounts.

Current study: Patient values and an integrated comprehensive health record system

There is some evidence that psychosocial interventions may be effective in treating people from HNHC populations.¹⁰ As HNHC patients utilize services across medical, social, and behavioral agencies, improvement in the health of these patients can be achieved by integrating data from all these agencies in addition to increasing engagement with them by setting patient-centered goals.⁸ Patient-centered goals take the form of identifying the patient values, an engagement strategy that has been well documented in the areas of chronic pain management¹¹ and mental health.¹² A values-based approach considers an individual's "important goals and desires for the way they want to live their life, rather than under the control of social pressures, for example, or experiences they wish to avoid."¹¹ Focusing on patient personal values, not just their medical conditions, will enable identification of the internal as well as systemic barriers that may be preventing patients from achieving health-related goals.

A complementary theory (self-determination theory¹³) suggests that people are more motivated to engage in change when they themselves make the decisions around those behaviors (autonomy), when they can see some form of tangible results (competence), and when they engage in behavioral change with people (relatedness). The values-driven approach is an inherently autonomous process for patients, as they decide how they need to behave in the service of personal, fundamental beliefs. A significant factor in the successful implementation of such a psychological approach that is scalable and usable by clinicians with a wide variety of training and experience is a set of structures that guide the intervention and gather results. Just such a bespoke structure was designed and integrated into a comprehensive health record system—namely, the Unified Care Continuum Platform (UCCP).

UCCP integrates data from the community (ie, linking patient data across medical and social agencies) and community resources (mapping needs to resources), providing the tool for effective care coordination. This includes more than 14 million service utilization records from medical agencies (eg, hospital systems, health insurance and payer systems, ambulatory clinics, behavioral health systems) along with social agencies (eg, food pantries, shelters, housing agencies, police departments, emergency medical services). By linking data from patient visits to various systems, communication gaps between agencies (that work independently) are bridged to provide a complete view of utilization and needs, as well as identify common clients and service gaps in the community. This helps to overcome systemic barriers to health that might exist and reduce duplication of services. In addition to linking data sets across social and medical agencies, UCCP facilitates resource referrals between providers at different agencies. UCCP produces patient handouts that are easily readable as a mechanism to improve ownership of the data for a patient, so that providers can share the care plan with the patient (not just other providers) and keep patient values at the center of the work. UCCP also encompasses an integrated evaluation of the value-based approach, assessing multiple patient outcomes (to be described) using appropriate surveys. This paper reports the preliminary outcomes of the UCCP and values-based approach, and discusses the impact of these outcomes on the developing approach.

Methods

Based on the aforementioned definition of the HNHC patients, patients are selected after conducting data analysis on the most costly and complex patients of a payer system that works with HNHC patients. Specifically, the Patient Care Intervention Center (PCIC) in Houston, TX, applies the goal-centered approach to provide values-based intervention to HNHC patients.¹⁴ The patients selected are contacted by the care coordination team for enrollment in a 6-month program. During weekly meetings, the care coordinator prioritizes identifying patient goals and their associated values. In addition, care coordinators identify barriers that patients may experience in their attempts to reach goals and behave in service of their values, assisting them with resource coordination and acquisition of advocacy skills to ensure better access to health care and healthy habits.

Implementation of the values-based approach is monitored through regular reflective practice meetings and quarterly qualitative interviews with the intervention team. The outcome and success of the value-based intervention is analyzed through assessments that focus on different areas related to the patients' well-being. Table 1 shows the progression of tools, as well as unacceptable measures, per patient and provider feedback. The following assessments have been chosen after piloting different tools with the HNHC population.

Specifically, the Daily Living Activities scale (DLA 20) measures the daily functioning of the patients through 20 activities.¹⁵ DLA 20 is scored by the care coordinator, with higher scores indicating increased functioning. Depression is measured by the Patient Health Questionnaire (PHQ-9), which consists of criteria for diagnosing depression.¹⁶ The score for PHQ-9 runs from 1 to 27 (scores above 5 indicate

◀T1

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TABLE 1. PROGRESSION OF ASSESSMENT TOOLS UTILIZED OVER TIME

<i>Assessments given and data collected</i>	<i>Iteration 1 (2014–2016) 64 patients</i>	<i>Iteration 2 (2015–2018) 27 patients</i>	<i>Iteration 3 (September 2018–present)</i>
DLA-20	Collected	Collected	Collected
Readiness to change (reported by provider)	Collected	Collected	Collected
Root Cause Analysis*	Collected		
ACE**	Collected		
Social Determinants of Health:		Collected	Collected
-Neighborhood & Built environment		Collected	Collected
-Economic Stability		Collected	Collected
-Food & Nutrition		Collected	Collected
-Health & Healthcare		Collected	Collected
-Social & Community Context		Collected	Collected
WAI			Collected
URICA			Collected
PHQ-9			Collected
WBQs			Collected

Note: *Root Cause Analysis—Tool for identifying causal relationships and origins of problems; however, the information gathered did not lead to different actions or produce better outcomes. Additionally, the values-based model was more useful to get to the root cause; therefore, discontinued use of root cause analysis.

**Discontinued use of the ACE²² because scores were inherently high for the complex population and trauma revealed during the assessment did not inform the current intervention and had the potential to uncover issues the intervention team was not trained for, and were not within the scope of expertise and time frame of the intervention.

ACE, Adverse Childhood Experiences; DLA-20, Daily Living Activities scale; PHQ-9, Patient Health Questionnaire-9; URICA, University of Rhode Island Change Assessment; WAI, Working Alliance Inventory; WBQs, well-being questions.

varying degrees of depression). The University of Rhode Island Change Assessment (URICA) is a 32-item tool that measures stages of change in the client on 4 continuous scales: precontemplation, contemplation, action, and maintenance.¹⁷

The Working Alliance Inventory (WAI) traditionally evaluates the level of alliance between a patient and a psychotherapist; however, with author permission, the tool was modified to include appropriate language (eg, “therapist” to “provider”).¹⁸ The WAI requires both the patient and the care coordinator to complete, describing the alliance with reference to “the concepts and qualities related to goals, tasks and bonds.”¹⁸ Additionally, patients were asked a series of general questions on their well-being, such as congruency of their behavior and values, feelings of hopelessness, and level of health engagement (referred to as well-being questions [WBQs]). WBQs were reported on a 10-point sliding scale from *never* to *always*. Each of these assessments was to be collected at different time points: DLA-20 was collected every month for the whole program (ie, 6 times); PHQ-9, URICA, WBQs, and WAI were collected 3 times (baseline, 3 months, and 6 months).

Ethical considerations

When engaging in the intervention, all participants provide informed consent for their non-identifiable data to be collated and aggregated for further analysis. Additionally, ethical approval for analysis of secondary data and staff participation was provided by the ethics committee at the University of Southampton on February 5, 2019 (ERGO ID: 46150).

Results

Preliminary outcomes are reported from this small sample (*n* = 18) pilot study and where results have shaped the intervention design. Outcome data were non-normally distributed, and the use of parametric tests would be inappropriate.

Therefore, data were analysed using a Wilcoxon signed-rank test to assess any differences over time.¹⁹ Regarding time points of data collection, care providers aimed to get assessments completed by predetermined dates; however, given the nature of the intervention (ie, respecting the values of the patient), actual dates varied. Table 2 reports demographic information and Table 3 reports on actual data collection time points.

In analysing outcome data, the research team focused on the first 2 time points for the PHQ9, URICA, WBQs, and WAI because only 1 patient completed T3 data. At baseline, patients reported mild depression (median [Mdn] = 3.00), with no significant change in score over time (Mdn = 6.501, *T* = .730, *P* > .05). Participant data show that they reported being in contemplation phase at baseline (Mdn = 9.00) and there was no change at Time 2 (Mdn = 9.28, *T* = -1.10, *P* > .05).

TABLE 2. PATIENT DEMOGRAPHICS

<i>Demographic information</i>	<i>n</i>	<i>%</i>
Sex		
Male	7	37
Female	11	58
Transgender	1	5
Age (years)		
18–25	0	0
26–35	4	21
36–45	1	5
46–55	8	42
56–65	6	32
Ethnicity		
Hispanic	4	21
Non-Hispanic white	15	79

◀T2
◀T3

TABLE 3. TIME POINT OF DATA COLLECTION

<i>Days since enrolment when tool completed</i>						
	<i>T1</i> <i>Mdn (M)</i>	<i>T2</i> <i>Mdn (M)</i>	<i>T3</i> <i>Mdn (M)</i>	<i>T4</i> <i>Mdn (M)</i>	<i>T5</i> <i>Mdn (M)</i>	<i>T6</i> <i>Mdn (M)</i>
URICA	n=11 24 (22.36)	n=9 82 (96.11)	n=1 Day 139	-	-	-
PHQ-9	n=11 22 (24.18)	n=9 96 (98.00)	n=1 Day 139	-	-	-
WAI	n=11 37 (34.27)	n=9 92 (96.71)	n=1 Day 139	-	-	-
WBQs	n=11 24 (25.81)	n=9 82 (95.77)	n=1 Day 139	-	-	-
DLA-20	n=11 24 (34.54)	n=8 66 (66.25)	n=7 100 (100.71)	n=7 128 (127.85)	n=6 160 (157.66)	n=2 185.5 (185.5)

DLA-20, Daily Living Activities scale; M, mean; Mdn, median; PHQ-9, Patient Health Questionnaire-9; URICA, University of Rhode Island Change Assessment; WAI, Working Alliance Inventory; WBQs, well-being questions.

To assess the WBQs, the research team broke them down into topic and compared across time points. At baseline, participants reported infrequent feelings of hopelessness (Mdn=0, mean [M]=1), and these levels increased at T2 (Mdn=4, M=4), but this change was not significant ($T=1.34$, $P>.05$). Patients reported a moderate congruency between their behaviors and their values at baseline (Mdn=5, M=5.55), and this did not change significantly over time (Mdn=7, M=6.11, $T=.272$, $P>.05$). Similarly, patients initially reported a moderate to high amount of health engagement (Mdn=8.25, M=7.22) and this was retained at T2 (Mdn=8.5, M=8, $T=.184$, $P>.05$).

Patients completed the WAI 3 times, but providers completed it once. To compare appropriate scores, the research team used Spearman's Rho to correlate the days when each assessment was done and found that providers completed the WAI around T2 ($r_s(5)=0.975$, $P=.005$). Patients reported strong working alliances at T2 (Mdn=58.0). Providers reported alliances as slightly lower (Mdn=42.0), but they did not differ significantly ($T=-1.69$, $P>.05$). Further, neither patients nor providers differed on their ratings on the individual subscales.

DLA 20 had very few patients reporting on T5 and T6, so those were eliminated from the analysis. From T1 (Mdn=44.00) to T4 (Mdn=51.00), DLA 20 scores improved significantly over time ($T=2.36$, $P=.018$, $d=.89$). There were no other significant differences; however, 2 trends were found. From T1 to T3 (Mdn=46.66, $T=1.82$, $P=.068$) and T3 to T4 ($T=1.82$, $P=.068$) scores increased, suggesting a trend toward improvement in patient daily functioning, even within a short time frame.

Discussion

This project sought to evaluate a novel intervention that integrates a psychological, values-based approach with coordinated care management. This pilot study found that

patients' daily functioning changes significantly over a 4-month period. The significant DLA 20 result shows that these HNHC patients have experienced an increase in their daily functioning, providing support for the overall intervention. Although the DLA 20 is completed by providers, and therefore might carry an inherent scoring bias, the same pattern was not found with the provider-completed WAI. That is, arguably, if the provider was biased, then the WAI scores should show signs of this. In fact, providers rated the strength of their working alliance with patients lower than patients did, suggesting that patients felt a strong bond with their provider. This may suggest that the values-based approach had a positive effect on the relationship between providers and patients, which, as is known from research in mental health, can influence outcomes.²⁰

Additionally, the nonsignificant results from patient-completed tools is only from 2 time points (ie, 3 months), as data are not available to support any further conclusions as yet. Baseline data suggest that patients have mild levels of depression, which is consistent with general population sample data.²¹ Most patients reported being in contemplation phase, which is ideal for providers to foster motivation and engagement in change. Once more data are available, it will be interesting to note outcomes related to stage of change. It is possible that these patients, being in contemplation phase, are more motivated to begin making behavioral changes and to engage than those who may be in precontemplation phase. Although the WBQs are not from a validated questionnaire, they are a useful source of information about how hopeless patients are feeling and how congruent to their values they feel they are living.

The work reflects the guidance provided by the National Academy of Medicine⁷ in a number of ways—particularly around enabling good use of data generated by clinicians through a UCCP, explicitly linking the person to their

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context through enabling conversations about goals in the service of values, and ensuring robust evaluation of outcomes that closely match the aims of the intervention.

Impact on approach

All assessments were conducted on UCCP, and providers sometimes used the questions as a means to engage with the patient or to inform their care plans. This is an important note; researchers rarely identify the inherent impact that evaluation can have, and this pilot testing has shown how useful it can be to embrace that element and allow it to strengthen the bond between provider and patient.

Additionally, there was considerable variance when earlier time points were collected; however, this appears to be decreasing over time, as shown in Table 3. It is anticipated that this reflects the initial phase of implementation and that time points of data collection will become more consistent over time. However, providers felt that initial implementation varied for the population because of clients' literacy levels. Clients did not disclose their inability to read or comprehend the questions being asked but rather ended the session. As time went on, the intervention team "assessed" literacy levels outside of the assessments by asking clients to perform simple tasks, "tell me how to spell your doctors name" while looking at the business card or "pick a provider from the list and tell me the phone number." Understanding literacy level was essential in completing the assessments on time for follow-up assessments in a Q&A format.

Also, providers found that the use of more visual approaches was beneficial for this client group. The WBQs are completed using a visual sliding scale with which patients easily communicated their responses. This suggests that there is a need for a better mechanism of assessments, pictorial or audio-visual integrated, rather than purely textual. It is key that qualitative data be collected from patients to understand the actual reason for variance in data collection, as it could be related to patient needs and, therefore, the evaluation aspect would be adapted to reflect this. Having this knowledge can influence how assessments are administered in the future on initial contact.

A patient-facing quality-of-life instrument could allow for a more accurate assessment of the desired goals of patients achieving agency or empowerment. Therefore, the intent is to include such a tool in the next iteration. It would be useful to triangulate these quality of life data with those collected on the social determinants of health (Table 1) and the service utilization data that are routinely collected. An analysis of the associations between these data may reveal a great deal about community and service factors and their relationship with individual factors linked to engagement in change, which in turn may help inform more seamless referral processes.

Conclusions

Although this report concerns a small sample and short time frame, preliminary results suggest that the values-based intervention and integrated UCCP have a positive impact on HNHC patient daily functioning. Results informed the development of the approach; specifically, to document how the evaluation influences patient-provider interactions, find novel methods of data collection for those with low lit-

eracy levels, and the need to include the voice of the patient in future work. This pilot study is the first step in disseminating the impact of the values-based approach with an integrated electronic health recording system to enhance patient engagement and care coordination.

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Author Disclosure Statement

The authors declare the following potential conflicts of interest: Drs. Barker and Maguire are currently employed by the University of Southampton, which has a financial relationship (ie, contract) with the nonprofit Patient Care Intervention Center (PCIC). Dr. Das, Mr. Mahata, and Ms. Bryant are employed at PCIC. Dr. Buck is employed by PCIC and 25% of his time and salary comes from PCIC. Dr. Buck is also employed by the University of Houston (UH) College of Medicine and 75% of his time and salary comes from UH.

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