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

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All authors have completed the conflict of interest form. Dr. Barker and Dr. Maguire are currently employed by the University of Southampton, which has a financial relationship (i.e. contract) with the non-profit 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 College of Medicine and 75% of his time and salary comes from UH.

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Abstract (250 words max)

**Objectives:** To evaluate a novel intervention which 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).

**Setting:** 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.

**Methods:** 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 wellbeing. Additionally, this paper reports preliminary findings from qualitative monitoring of provider experiences implementing the values-based approach and integrated evaluation.

**Results:**  HNHC patients improved on their daily functioning over 4 months but we did not find any other significant changes over time. Patients self-reported mild depression, strong working alliances with their provider, being in the contemplation phase of change, and moderate wellbeing. There was also variation when patients completed the assessments and data points were collected.

**Conclusions:** Although it 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.

Key Words: *values-based intervention; complex needs; high needs, high cost; care coordination*

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**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).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, the Centers for Medicare and Medicaid Services5 data showed that in Harris County, 6,000 HNHC patients incurred more than $1 billion in health care costs. HNHC patients’ complex needs are due to the interplay between profound biopsychosocial needs and a health system that is unresponsive and unaccommodating. For the purposes of this paper, we define HNHC patients as those who have two or more co-morbid chronic conditions along with one or more social, mental and behavioral needs (in addition to multiple ER visits for unmanaged chronic conditions) and cost the system over $130,000 per year. Work by the National Academy of Medicine7 describes the essential directions in which healthcare in the US needs to change in order to serve the population better. Of particular note are a number of the recommended action priorities around: 1) delivering more effective healthcare 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. Since 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. We must alter our engagement strategies with this group 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 involved9. 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 (CHR) System**

There is some evidence that psychosocial interventions may be effective in treating people from HNHC populations.10 As the 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 the patients, by setting patient-centered goals.8  Patient-centered goals take the form of identifying the values of the patient, 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 By focusing on patient personal values, not just their medical conditions, we will be able to identify the internal as well as systemic barriers that may be preventing patients from achieving health-related goals.

A complimentary 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 which 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).

The UCCP integrates data from the community (i.e. linking patient data across medical and social agencies) and community resources (mapping needs to resources), providing the tool for effective care coordination. This includes over 14 million service utilization records from medical agencies like hospital systems, health insurance and payer systems, ambulatory clinics, and behavioral health systems, along with social agencies like food pantries, shelters, housing agencies, police department and Emergency Medical Services. By linking data from patient visits to various systems, communication gaps are bridged between agencies (that work independently) 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 datasets across social and medical agencies, the UCCP facilitates resource referrals between providers at different agencies. The 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 the values of the patient at the centre of the work. The UCCP also encompasses an integrated evaluation of the value-based approach, assessing multiple patient outcomes (described below) 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 definition of the HNHC patients mentioned earlier, 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 selected patients 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 the patient 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 healthcare 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 The DLA 20 is scored by the care coordinator, higher scores indicate 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 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 four 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 (e.g. “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, we asked patients a series of general questions on their wellbeing, such as congruency of their behavior and values, feelings of hopelessness, and level of health engagement (referred to as wellbeing questions (WBQs)). WBQs were reported on a 10-point sliding scale from never to always. Each of these assessments were aimed to be collected at different time points. The DLA-20 was collected every month for the whole program (i.e., 6 times), PHQ-9, URICA, WBQs, and WAI were collected 3 times (baseline, 3 months, and 6 months).

**Ethical Considerations**

All participants provide informed consent when engaging in the intervention 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 Feb 5, 2019 (ERGO ID: 46150).

**Results**

We report preliminary outcomes from this small sample (*n* = 18) pilot study and where results have shaped the intervention design. Outcome data was non-normally distributed, and the use of parametric tests would be inappropriate. Therefore, data was analysed using a Wilcoxon Signed Rank to assess any differences over time.19  Regarding time points of data collection, care providers aimed to get assessments completed by the predetermined dates, however, given the nature of the intervention (i.e. respecting the values of the patient) actual dates varied. Table 2 reports demographic information and Table 3 reports on actual data collection time point.

In analysing outcome data, we focused on the first two time points for the PHQ9, URICA, WBQs, and WAI because there was only one patient who completed T3 data. At baseline, patients reported mild depression (*Mdn* = 3.00), with no significant change in score over time (*Mdn* = 6.501, *T* = .730, *p* > .05). Participant data shows 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).

To assess the WBQs, we broke them down into topic and compared across time points. At baseline, participants reported infrequent feelings of hopelessness (*Mdn* = 0, *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 significantly change 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).

For the WAI, patients completed this tool three times, but providers completed it once. To compare appropriate scores, using Spearman’s Rho, we correlated the days when each assessment was done and found that providers completed the WAI around T2 (*rs*(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.

The DLA20 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), DLA20 scores significantly improved over time (*T* = 2.36, *p* = .018, *d* = .89). There were no other significant differences, however, two 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 towards improvement in patient daily functioning, even within a short time frame.

**Discussion**

This project sought to evaluate a novel intervention which integrates a psychological, values-based approach with coordinated care management. In this pilot study, it was found that patients’ daily functioning significantly changes over a 4-month period. The significant DLA20 result shows that these HNHC patients have experienced an increase in their daily functioning, providing support for the overall intervention. Although the DLA20 is completed by the 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 the 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 we know from research in mental health, can influence outcomes.20

Additionally, the non-significant results from patient-completed tools is only from two time points (i.e. 3 months), we just do not have the data to support any further conclusions as of yet. Baseline data suggests 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 we have more data, 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 the patient is 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 context through enabling conversations about goals in the service of values, and ensuring robust evaluation of outcomes which closely match the aims of the intervention.

**Impact on Approach**

All the assessments were conducted on the UCCP, and providers sometimes used the questions as means to engage with the patient or to inform their care plans. This is an important note, as researchers, we rarely identify the inherent impact that evaluation can have, 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. We anticipate 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 due to client’s literacy level. 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 the literacy level was essential in completing the assessments on time for follow up assessments in a Q and A format.

Also, providers found that the use of more visual approaches were beneficial for this client group. The WBQs are completed using a visual sliding scale where patients easily communicated their responses. This suggest that there is a need for a better mechanism of assessments, pictorial or audio-visual integrated, rather than purely textual. It is key that we collect qualitative data from the patients to understand the actual reason for variance in data collection, as it could be due to patient needs and therefore we would adapt the evaluation aspect 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 our desired goals of patient’s achieving agency or empowerment. Therefore, in our next iteration we intend to include such a tool. It would be useful to triangulate this quality of life data with that collected on the social determinants of health (Table 1) and the service utilization data that is routinely collected. An analysis into the associations between these data may tell us a great deal about community and service factors and their relationship with individual factors linked to engagement in change, which may in turn help inform more seamless referral processes.

**Conclusions**

Although we report on a small sample and short time frame, preliminary results suggest that the values-based intervention and integrated UCCP has 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 literacy levels, and the need to include the voice of the patient in future work. This pilot study is the first step of 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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