

“Having a Normal Life”

A Qualitative Study on Client Goal-Setting Within a Health Care and Social Needs Navigation Program

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Abstract: Client goals within healthcare and social needs navigation programs are neither well understood nor incorporated into ambulatory care practices. This study provides a qualitative analysis of client-established goals within the Interprofessional Care Access Network (I-CAN), a community-based health care and social needs navigation program. One hundred eleven client goal lists were analyzed using conventional content analysis. Twenty-two codes were developed and grouped into 4 main categories including Physical/Mental Health, Social/Social Services, Health Care System, and Daily Living. The results of this study offer insight into client goals within health care and social needs navigation programs and provide suggestions for future research.
Key words: goals, home health nursing, nursing, patient navigation, social determinants of health

COLLABORATIVE PATIENT-PROVIDER goal-setting, defined as an ongoing discussion of desired patient outcomes between patient and provider (Von Korff et al., 2002),

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has been studied within the context of rehabilitation (Hurn et al., 2006; Sugavanam et al., 2013), chronic pain (Sibthorpe & Gardner, 2007), and mental health (Arens et al., 2018). Formal goal-setting has been shown to enhance effectiveness of interventions among the elderly (Farhney et al., 2010; Yuri et al., 2016) and improve quality of life via individualized activities (Parsons et al., 2011). Furthermore, collaborative goal-setting is important because it orients care toward patient preferences (Cheng, 2017; Toto et al., 2015), promoting patient-centered care. Patient-centered care, defined by the Institute of Medicine as “care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions” (Kala, Baruah, & Unnikrishnan, 2017, p. 365), has been shown to positively impact the provider-patient relationship (Anderson, 2002) and improve health outcomes (Robinson et al., 2008). Respect for patient preference is a core principle of patient-centered care;

however, patient goals and preferences have gone largely unaddressed within the context of health care and social needs navigation programs.

Collaborative goal-setting within low-income patient populations merits special consideration. Evidence has shown that low-income patients are less likely to receive patient-centered care (Verlinde et al., 2012) and less likely to be involved in health care decision making (Kaplan et al., 1995). Providers may be disinclined to cede decision making to patients perceived as having low health literacy and/or education (Kangovi et al., 2017). Low-income populations are more likely to be affected by chronic disease (Winkleby et al., 1992), have lower rates of access to medical care (Shi & Stevens, 2005), and experience a high degree of unmet social needs, which can be a barrier to health care and increase complexity and cost of care.

It is well established that social determinants of health (SDH) influence health outcomes (Marmot & Wilkinson, 2005), and numerous federal initiatives have provided support for incorporation of SDH into health care settings. These SDH programs, while beneficial to their low-income participants, tend not to incorporate patient goals/preferences (Beck et al., 2018). It is especially important to prioritize patient goals in low-income groups, given the high degree of unmet social needs among these populations.

As of this writing, we know of no study exploring patient goals/preferences in health care and social needs navigation programs. To fill this gap in knowledge, we conducted a conventional content analysis of patient goal lists constructed by patients and student-led interprofessional care teams within a health care and social needs navigation program. These results can be used to further the understanding of goals that low-income patients with a high degree of unmet social needs hope to achieve within similar programs. By neglecting to collect and utilize patient preference to guide care, programs risk addressing only the priorities of health care providers,

which may or may not be aligned with patient priorities.

METHODS

Intervention

The Interprofessional Care Access Network (I-CAN) is a community-based academic practice model that provides health care and social needs navigation across 5 low-resource urban neighborhoods and rural communities (Wros et al., 2015). I-CAN has demonstrated that student team interventions focused on SDH can affect the health and well-being of individuals and populations. Student teams made up of nursing, medical, pharmacy, nutrition, and/or dental students conduct weekly home visits under faculty supervision to assist clients in addressing SDH and provide care coordination and health education. Student teams meet with clients in their homes on average of once a week for 60 to 90 minutes. These times in the home are used to establish and develop the provider-client relationship. I-CAN clients often stay with the I-CAN program over multiple terms, in which case trust is established and built upon by multiple student teams and faculty. Faculty members maintain contact with clients over multiple terms, ensuring continuity of care.

Population

I-CAN clients are referred by community partners on the basis of social and/or health care utilization criteria. Most clients are publicly insured and have 12 or fewer years of education (Table 1). I-CAN clients are often poor and socially isolated. Furthermore, they may have a history of substance abuse and trauma, factors that can lead to mistrust of both the health care and social service systems. Most clients have complex medical issues and face multiple barriers in accessing medical care. These barriers are often related to poverty, disability, and language barriers. Clients often wish to improve their health, but medical priorities may not be able to be addressed until basic social needs to enable access to care are met.

Table 1. Client Demographics (N = 111)

	n (%)
Age	
20-39	22 (20)
40-64	45 (41)
65-89	28 (25)
No response	16 (14)
Insurance status	
Medicare	23 (21)
Medicaid	62 (56)
Private	3 (3)
Uninsured	5 (5)
No response	18 (15)
Years of education	
0-4	7 (6)
5-8	12 (11)
9-12	36 (32)
13-18	27 (24)
19+	2 (2)
No response	27 (24)
Race	
Asian	22 (20)
Black or African American	3 (3)
White/Caucasian	50 (45)
>1 race	1 (1)
No response	35 (32)
Place of birth	
US-born	59 (53)
Non-US born	33 (30)
No response	19 (17)

Data collection

Data collector training

I-CAN data are collected by student data collectors. To ensure data integrity, I-CAN student data collectors receive study-specific training on data collection from experienced faculty members and I-CAN staff. This training includes faculty lectures, interactive role-playing sessions, and simulation, all within a daylong study orientation. In addition, students complete Web-based data collection training modules prior to orientation. Students work closely with faculty during data collection, and faculty members review all data collected on a weekly basis.

Since trust is an essential component of the health care provider-client relationship (Forchuk et al., 2000) and essential to the I-CAN program, students receive specific training in trust building. Trust building is discussed at study orientation, and I-CAN students participate in multiple simulation experiences to learn trust building in home-based care from experienced faculty members. In addition, the I-CAN rotation occurs later in the student’s academic program, enabling I-CAN students to apply trust-building experience from earlier clinical experience.

Data collection tool: The Client Goal List

For each client within the I-CAN program, student teams conduct an initial intake assessment to collect social, health, and health care usage data. As a part of this intake, student teams use the Client Goal List (CGL), an internally developed tool to record client goals. The CGL includes fields for identifying information, followed by blank spaces for entering free text. The CGL is administered via iPads by student data collectors during weekly visits. To populate the CGL, students and clients work together to establish goals, which students record in the CGL. The completed CGL is used to guide the interventions over subsequent weeks and months in which clients participate in I-CAN.

Data collection procedure

Client goal data were collected from June 2015 to June 2017 as a part of the I-CAN intervention; this study sample includes 111 CGLs completed within this time frame. Of the 111 clients in this study, 29 preferred to communicate in a language other than English, in which case an in-person or phone-based certified interpreter was used.

Goal-setting and the CGL were introduced within the first 3 in-home client visits. Student data collectors began this conversation by asking “What are your goals?” Goals were broadly defined as what the clients hoped to achieve within I-CAN or how they hoped their life situation could be improved with it. These questions were intentionally open-ended for clients to formulate and set their goals

directly. In some cases, clients are ready to establish goals within the first couple of visits. In other cases, clients were not ready to establish goals or did not know what goals they hoped to achieve. In these instances, student data collectors continually discussed goals on an ongoing weekly basis and established goals as they arose throughout I-CAN weekly home visits. For some clients, goals cannot be identified until trust and rapport are established within the relationship. Student data collectors then record goals on the CGL after they are identified at any point in the intervention.

Analysis

Data were analyzed in DeDoose (“De-doose,” 2016) by the 2 authors on the program evaluation team (K.L., K.J.B.). Conventional content analysis (Kondracki et al., 2002) with a focus on manifest content (Vaismoradi et al., 2013) was used to analyze all data. In line with inductive category development (Mayring, 2000), the authors did not construct hypotheses prior to data analysis.

The process began with data immersion by the 2 authors/coders. Both began by reading the data set in its entirety and writing initial thoughts, noting illustrative quotes, and identifying possible themes. The coders then reread manuscripts to begin to hypothesize codes, which were then grouped into categories (Elo & Kyngäs, 2008). Each coder formalized codes into independent codebooks, complete with code definitions and example quotations. Coders then reconciled their codebooks through an iterative process during weekly meetings that included reimmersion within the texts. After the coders agreed on a codebook, the transcripts were coded in their entirety by both coders, and codes and content were analyzed for underlying meaning. The 2 coders calculated an interrater reliability score of 0.89 using Cohen’s κ within Dedoose, which was deemed sufficient according to the Klaus criteria (Klaus, 1980). The results of the analysis and grouping of codes into categories were reviewed and adapted through consensus with the other authors (P.W., K.B.J.).

Ethical approval

All procedures performed in the I-CAN program were reviewed and approved by the Oregon Health and Science University institutional review board for the protection of Human Subjects (reference no. 0000009409) and conducted in accordance with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

RESULTS

Twenty-two codes were identified, which were grouped into 4 categories including Physical/Mental Health, Social/Social Services, Health Care System, and Daily Living (Table 2).

Table 2. Categories and Codes

Category	Code(s)
Physical/ Mental Health	Disease management
	Pain management
	Physical activity
	Mental health
	Substance use
Social/Social Services	Weight management
	Housing
	Nutrition
	Transportation
	Social interaction/isolation
	Benefits
	Food access
Health Care System	Legal/documentation
	Utilities
	Appointment with provider
	Medications
Daily Living	Insurance
	Change provider
	Instrumental activities of daily living
	Durable Medical Equipment
	Nonmedical household goods
	Maintain independence

Physical/Mental Health

The Physical/Mental Health category included codes related to desired change in physical or mental health (Table 3). The *Disease management code* highlighted goals related to physical management of disease (“Insulin and CBG management,” “Keep blood sugar under 150”). Clients often established goals related to learning about their specific disease, getting help with disease management, or understanding various forms of treatment.

The *Pain management code* was used often. Clients expressed a wide range of goals related to pain management and pain mitigation (“Visit podiatrist about pain and numbness,” “Address severe lower back pain”). Some clients expressed a wish to manage their pain, while others sought to wholly reduce or resolve their pain. Furthermore, some clients mentioned specific pain-alleviating treatments including pharmacological solutions (“Get medications for back pain”) and nonpharmacological solutions (“Acupuncture for pain”).

Table 3. Physical/Mental Health Category

Code	Quote
Pain management	“Chronic nerve pain”; “To alleviate pain/stiffness in hands”
Physical activity	“To engage in aerobic therapy”; “Improve strength so able to walk”
Mental health	“Reestablish care with mental health provider”; “CAM for anxiety (coping techniques)”
Substance use	“Smoking cessation”; “Attend AA meetings”
Weight management	“Lose weight”; “To maintain weight”

Abbreviations: AA, Alcoholics Anonymous; CAM, complementary and alternative medicine.

Social/Social Services

The next category identified was Social/Social Services, which included codes related to clients’ social lives (Table 4). Social goals were broadly distributed, but *Housing* emerged as a common code. Needs related to housing were diverse—clients referenced housing within the context of improvements (“Explore/apply for assisted living,” “Handicap-accessible housing”) and economic concerns (“Financial support/new housing” and “Stable housing”). Clients often struggled with the cost of housing or were in housing that was not suited to their needs/desires. The codes *Nutrition* and

Table 4. Social/Social Services Category

Code	Quote
Housing	“Rid home of cockroaches”; “Acquire affordable long-term housing”
Nutrition	“Nutrition and swallowing”; “Meal planning”
Transportation	“Understand and use Ridetocare”; “Set up transportation for grocery shopping”
Social interaction/isolation	“Self-care—socialization”; “Connect with Muslim org. for support”
Benefits	“Switching SSI payee to her brother”; “Increase SNAP benefits”
Food access	“Locate halal food resources”; “Substitute person to pick up food box”
Legal/documentation	“Wife to U.S.”; “Replace Oregon ID”
Utilities	“No hot water for past week”; “Fix heat at residence”

Abbreviation: SNAP, Supplemental Nutritional Assistance Program.

Food access were also frequently used. Most commonly, clients indicated goals related to improved nutrition, which were sometimes related to other codes such as *Disease management* (“Change diet—include more vegetables,” “Diabetic nutritional recipes”). Clients sought to improve *Food access* in various ways (“Increase SNAP benefits,” “Set up food box delivery”). Meals on Wheels and the Supplemental Nutritional Assistance Program were mentioned often, although food banks were rarely noted. This could be due to food banks being a temporary intervention, as opposed to an ongoing focus of a long-term intervention.

The *Transportation* code was applied frequently in the context of getting to medical appointments (“Transportation to clinic,” “Get transportation arranged for hospital”), learning about how to use transportation systems (“Navigate public transportation system”), or obtaining a bus pass (“Get honored citizens bus pass”). Most clients planned to rely on public transportation networks for transportation; there was no mention of cars and very few mentions of bicycles.

Other codes were developed within the category of Social/Social Services to capture the wide-ranging social goals established by clients. These included *Social interaction/isolation* (“Animal companion—buy a cat”), *Legal/documentation* (“Obtain ID for housing”), *Benefits* (“Reapply for SSI”), *Utilities* (“Fix heat at residence”), and *Employment* (“Find job that’s not so hard on back”).

Health Care System

The Health Care System category captured all codes related to seeking and navigating the health care system. The *Appointment with provider* code was applied often, demonstrating the ongoing difficulties clients had in navigating the health care system. There was a great deal of variation within the *Appointment with provider* code across type and urgency of appointment. For example, clients sought providers such as dentists, mental health counselors, surgeons, primary care providers, gynecologists, and others. Urgency of service

ranged from high (“Treatment for brain tumor,” “Rectal bleeding—colonoscopy”) to medium/low (“Get family vaccinated for Green card,” “Attend PT appts”). Often, these goals included rescheduling missed appointments (“Reschedule no show dental appt.”), scheduling follow-up appointments (“Follow up dental appointment”), finding transportation to appointments (“Transportation for renal appointment”), or switching providers and/or clinics (“New PCP—possibly not at Clinic”). Some sought interpretation services for appointments (“Verify interpreter request for all PT appts.”), and many named scheduling/attending physical therapy (“Return to PT”).

Many goals fell within the *Medications* code (“Medication refills needed,” “Review all medications”). Confusion around medication was common; this suggests an overall lack of knowledge and understanding of safe medication practices. *Insurance* and *Change provider codes* were also identified; examples can be seen in Table 5.

Daily Living

Codes were established that fell within the category of Daily Living. These codes

Table 5. Health Care System Category

Code	Quote
Appointment with provider	“Visit PCP about tension headaches”; “Top surgery”
Medications	“Continue to take Lisinopril”; “Medication reminder charts”
Insurance	“Reconcile bill with glaucoma assoc.”; “Senior Services OHP? Can I get?”
Change provider	“Find trans-competent caregiver”; “Find female primary care provider”

Abbreviations: OHP, Oregon Health Plan; PCP, primary care provider.

captured the wide range of goals that were home-based and nonmedical in nature. Clients often sought assistance with various *Instrumental activities of daily living (IADL)* (“Close bank account,” “Can’t work dishwasher”). Clients primarily wished to organize their home lives, using phrases such as organize, maintain, and activate. The aspects of their lives in which they sought organization varied widely from completing errands to reorganizing finances. Overall, the frequency of *IADL* is suggestive of a high need for assistance with nonmedical tasks that require individualized aid.

The *Nonmedical household goods* code (Table 6) illuminated clients’ object-oriented goals including obtaining or fixing non-medical goods (“Fix computer,” “Books for daughter”). The *Durable Medical Equipment* code captures the variety of medical equipment often mentioned; these goals related to glasses, custom shoes, pill boxes, and wheelchairs/walkers.

DISCUSSION

The purpose of this article is to better understand goals that clients hope to achieve within the realm of health care navigation

and social services. These goals are important in that they may be very different from those that are typically identified by providers. Furthermore, clients may be unlikely to mention these goals, increasing the likelihood that unmet social needs act as hidden barriers to achieving health goals. The results indicate that although many client goals fell within similar categories, addressing the goals would require individualized care. Although service providers may intuitively understand that clients have diverse goals, and the nature of many of these goals may not surprise providers working with this population, at the time of writing, no evidence exists to describe client goals within SDH navigation program. It is essential that providers understand both individual goals and common goals within a population. In addition, health care and social service leaders who administer programs such as I-CAN have much to gain from a more thorough understanding of patient goals—most programs have been based on client *need* rather than preference.

Impact of social factors on access to care

The high number of goals related to making or changing appointments with providers points to the possibility that certain social conditions found within vulnerable populations interact to create barriers to attending appointments. Lack of access to transportation, childcare, hourly work obligations, and economic instability all limit individuals’ ability to attend appointments (Pesata et al., 1999).

It is well known by providers serving low-income populations that the US health care system is complex and difficult to navigate. These difficulties are exacerbated by financial and social limitations faced by low-income populations. Many I-CAN clients in this sample established making an appointment with a provider as a goal. The frequency of goals related to scheduling, rescheduling, and/or obtaining medical results indicates a substantial confusion and misinformation regarding the health system. Even when services were utilized, clients often needed assistance understanding instructions and

Table 6. Daily Living Category

Code	Quote
Instrumental activities of daily living	“Go shopping more easily”; “Help with running errands”
Durable Medical Equipment	“Get new toilet riser”; “Transition to four-point cane”
Maintaining independence	“Taking walks safely and independently”; “Preserve home to age in place”
Nonmedical household goods	“Obtain a single/twin mattress”; “Obtain tennis shoes through CHA”

accessing test results and information about their health. Increased clarity, frequency, and flexibility of communication related to appointments and test results could improve quality of care for clients. This could reduce the overall cost of missed appointments on the health care system.

Culture and goal conceptualization

A subset of the I-CAN population comprised refugees and immigrants (33% non-US born), many of whom have limited English proficiency (LEP). Unmet social needs were often exacerbated by clients' spoken language and/or immigration status. Language and immigration status affected many dimensions of access to services for I-CAN clients, a common experience among immigrant and refugee communities (Ramirez et al., 2008; Westberg & Sorensen, 2005). For LEP clients, navigating complicated clinic scheduling can be an insurmountable barrier and it was common for them to simply not schedule recommended appointments. Similarly, many clients sought to learn more about their prescription medication due to the standard of English-only language medication labeling. The necessity of interpreter services adds an additional layer of complexity in medical interactions. Access to, and renewal of, health insurance is uniquely burdensome since most enrolling information (insurance renewal forms, insurance information, etc) is primarily published and disseminated in English. In addition, the after-visit summaries are in English and of little use for the LEP client.

Goal-setting and views of health care are heavily influenced by culture and previous experience with the health care system. The process of "goal-setting" or the value of "client-centered" is foreign to many recently resettled refugee populations. I-CAN LEP clients may conceptualize goals differently. Somatic manifestation of posttraumatic stress disorder in the refugee population is well documented (Morina et al., 2017) and present among I-CAN clients, which has serious implications for goal-setting and communication in health care settings.

Future research

We recommend 2 areas of further research based on these findings. First, we recommend that research explore how navigation programs addressing health care and social needs could incorporate client goals related to unmet needs into ambulatory care practices. These results demonstrate the substantial breadth and complexity of what clients hope to achieve within social needs and health care navigation programs. The current health care movement toward patient-centered care includes patients as "co-producers of their lifelong health development" (Halfon et al., 2014); client goals must be considered to realize this vision.

Second, we recommend that research explore home visitation as a promising strategy for building trust in the health care system and obtaining unique information to include in planning effective primary care for marginalized patients and invaluable information for providers. Health care may have much to gain from a greater awareness of the social lives of clients outside of primary care offices and hospitals; thus, information is learned via home visit. Within I-CAN, variability in client preference and life situation necessitated tailored community-based and culturally competent assistance. Understanding needs from the client's perspective, within their home and community, was essential in affecting change within this study's population.

Limitations

The I-CAN program is based on patient-centered care and is driven by client preference, which the authors believe strengthen the program. However, this orientation toward patient-centered care creates 2 important limitations for this study. First, the open-ended nature of goal identification required that students reduce complex goals and ideas to list form. This necessitated interpretation on the part of the data collector. The framing of "goals" as part of the CGL was subject to variation between data collectors. Second, each conversation establishing goals was different. Goals were not selected from

predetermined categories but were instead identified in an open-ended manner over a period of discussions. These discussions varied in content and length, and this study did not incorporate the full content of these discussions. The students administering the intervention likely influenced the type of goals set by the clients. In addition, clients themselves sometimes looked to student data collectors for guidance on what *can* be achieved within the I-CAN program. The student data collectors may then provide recommendations that reflect their profession and experience.

This study was also limited by potential variation between data collectors. Client goal data were collected by more than 40 different student data collectors over 2 years as a part of the wider I-CAN program. To minimize the impact of this potential limitation, students received standardized training on study protocols, data collection, and bias. Despite this, variation among data collectors may have influenced data collection, creating variability in client goal data.

Finally, trust in the provider and the health care systems' ability to solve problems is essential for successful patient navigation and communication and may limit the conclusions drawn from this study. While student teams and faculty members intentionally

worked to build relationships with clients, it is possible that clients were not entirely forthcoming with their goals. Although nursing consistently ranks as a highly trusted health professional role (Rutherford, 2013), previously established mistrust in the health care system could have been reflected in their participation within the I-CAN program. The most effective interventions occur within the context of open communication within a trusted relationship: if clients lacked confidence in the trustworthiness or ability of the health care team to address their problems, findings may not be reliable/complete.

CONCLUSIONS

It is well substantiated that low-income clients have a high degree of unmet social needs that present significant barriers to health and effective health care. Consistent with this understanding, results show that clients seek assistance across a broad range of domains. Many of these domains, however, fall outside the realm of typical ambulatory-based SDH coordination programs. To comprehensively address SDH in health care settings, we recommend a consideration of client goals/preferences within these programs.

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