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Survey Instruments to Assess Patient Experiences with Access and Coordination Across Healthcare Settings: Available and Needed Measures

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Abstract

Background—Improving access can increase the providers a patient sees, and cause coordination challenges. For initiatives that increase care across healthcare settings, measuring patient experiences with access and care coordination will be crucial.

Objectives—Map existing survey measures of patient experiences with access and care coordination expected to be relevant to patients accessing care across settings. Preliminarily examine whether aspects of access and care coordination important to patients are represented by existing measures.

Research Design—Structured literature review of domains and existing survey measures related to access and care coordination across settings. Survey measures, and preliminary themes from semi-structured interviews of 10 patients offered VA-purchased Community Care, were mapped to identified domains.

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Results—We identified 31 existing survey instruments with 279 items representing 6 access and 5 care coordination domains relevant to cross-system care. Domains frequently assessed by existing measures included follow up coordination, primary care access, cross-setting coordination, and continuity. Preliminary issues identified in interviews, but not commonly assessed by existing measures included: 1) acceptability of distance to care site given patient's clinical situation, 2) burden on patients to access and coordinate care and billing, 3) provider familiarity with Veteran culture and VA processes.

Conclusions—Existing survey instruments assess many aspects of patient experiences with access and care coordination in cross-system care. Systems assessing cross-system care should consider whether patient surveys accurately reflect the level of patients' concerns with burden to access and coordinate care, and adequately reflect the impact of clinical severity and cultural familiarity on patient preferences.

INTRODUCTION

Improving access to care and coordination of care are two main goals of modern models of delivering health care.^{1, 2} However, these two laudable goals can at times be at odds - providing speedy access to care can result in loss of continuity with a usual care provider (a key method of encouraging coordinated care), or result in care that is duplicative. Therefore, as improvements to access are pursued, it is crucial to measure and monitor changes to both access and care coordination. When increased access is provided through care across health systems, as with the implementation of the Veterans Choice Act (VCA) in the Veterans Health Administration (VHA)³ care coordination may become increasingly difficult. Such cross-system care is also an important issue for health systems and accountable care organizations across the U.S. given the potential impact of using multiple doctors⁴ and poor care coordination on resource use, health, and patient satisfaction.⁵ When patients access care across health systems it is particularly important to measure their experiences with care coordination (including continuity) to ensure that high quality care is being provided.

Many commonly used measures of health care access and coordination rely on administrative data, such as wait time to appointment or percentage of visits with one usual physician.⁶ Administrative data, however, can be difficult to compile across health care systems. In addition, administrative data may not fully capture patients' experiences or preferences related to access and care coordination. For these reasons, healthcare systems increasingly rely on patient surveys to monitor patient perceptions of ease of access or successful care coordination.^{7, 8} Yet, it is unclear how well currently available and widely used patient surveys address factors that influence patients' decisions about using care outside of their usual healthcare system, and patient experiences when accessing and coordinating cross-system care.

To address these issues, we conducted a structured review and assessment of existing validated measures of patient experiences with access and care coordination relevant to care across health systems. We included measures of continuity as reflecting a key strategy in achieving coordinated care. We then interviewed a small sample of VHA patients who were eligible for VA-purchased Community Care about their priorities regarding access and care

coordination, to start to explore patient priorities that were not represented by existing survey measures.

METHODS

Identifying Cross-System Access and Care Coordination Domains and Survey Items

Using published systematic reviews,^{9–13} conceptual or theoretical models,^{14–18} and landmark reports,^{19–23} we developed a preliminary list of thematic domains within the two broad categories of access to care and care coordination. Similar to other authors, we categorized care continuity as one aspect of care coordination,^{9,24} which was defined for this project as "the extent to which a series of healthcare services is experienced as connected and coherent and is consistent with a patient's health needs and personal circumstances,"¹⁰ and includes components of the AHRQ definition related to "the deliberate organization of patient care activities between two or more participants to facilitate the appropriate delivery of health care services."²²

We then conducted a structured literature review using Medline, Cochrane, and Web of Science databases to identify existing survey measures of patient experiences and satisfaction with access to care and care coordination and to further refine and clarify domains. Search terms included 'health care access', 'continuity of care', 'coordination of care', 'access measures', as well as more specific terms including 'primary care access measures', 'longitudinal continuity measures', and 'spatial access measures'. This search examined structured or systematic review articles from peer-reviewed research literature as well as non-research reports, and was conducted in early 2016. Literature published prior to 1974, published in languages other than English, or exclusively related to inpatient hospital care and/or emergency department care was excluded. Survey tools uniquely developed for use in only one study also were excluded, as we aimed to gather well-developed, commonly used, and validated instruments. A supplementary general web search was used to seek out additional non-research reports from governmental agencies and foundations and to identify articles providing validation for the survey tools included. Finally, we reviewed similar searches completed by researchers at the National Committee for Quality Assurance (unpublished) for any further survey measures not previously identified. A list of survey instruments measuring access to care and/or care coordination was created. This list was then reduced to include only survey instruments administered to patients, as the focus of this evaluation was to better understand patient experiences and satisfaction, and the wording of individual survey questions or items was obtained. Each item was then individually mapped to the relevant access or care coordination domain. For example, a survey item asking "Is it difficult to get a check-up there [clinic/doctor's office]?" was categorized as assessing the 'primary care access' domain. Two project team members independently categorized each survey item, and the categorization was reviewed by a third team member. Discrepancies were resolved via consensus discussions. In general, survey items were categorized in one of 11 domains; however in a few cases (n=11), survey items fit into more than one domain and were subsequently categorized in multiple relevant domains. For example, the item asking "How easy or difficult is it to get care in the evenings, on weekends, or holidays...?" was categorized as relevant to both the routine primary care and urgent access domains.

Patient Interviews

A pilot study of semi-structured interviews was conducted with Veterans who had considered whether to use VA-purchased Community Care, to determine the feasibility of interviewing patients to assess their experiences with cross-system care, and to conduct a preliminary exploration of themes that were not represented by existing patient surveys. These interviews were part of a rapid-cycle evaluation of patient experiences conducted to help inform VA development of a patient experience survey for Veterans eligible for VApurchased Community Care. We interviewed 10 Veterans from one VHA medical center who had been offered VA-purchased Community Care. Of those ten, eight had used VCA to pursue VHA-purchased Community Care, and two had opted to receive care at a VHA facility instead; seven were male and three female; eight were seeking specialty outpatient care and two were seeking primary care. Phone interviews were conducted in mid-2015 by trained interviewers using a semi-structured interview guide (Appendix A: Interview Guide). Three project team members contributed to detailed interview notes, and used a template approach to analyze the data, coding notes initially using the domains identified from our literature review, then adding new domains to represent unmappable themes. Any disagreements were resolved through discussion.^{25,26}

RESULTS

Access and Care Coordination Domains

Eleven access and care coordination domains relevant to patients considering or experiencing cross-system care were identified and are described in Table 1. Healthcare access consisted of six domains: 'primary care access',^{6–9, 15,20,27–31} 'specialty care access',^{8,30} 'urgent care access',^{9,20} 'spatial access' (including geographic and transportation barriers),^{8,11,14,15,27,29,31,32–37} 'communication access between visits',^{9,21,22,27} and 'cultural access' (including familiarity with patient's culture and language barriers).^{27, 29} The five domains related to care coordination included: 'longitudinal continuity',^{5,8,9,11,25,31,36,38–42} 'relational continuity' (defined as patient developing trust and respect for provider over time),^{10,11,23,25,29,36,39–46} 'informational continuity' (all providers have access to comprehensive patient information),^{5,10–12,14,21–23,25,36,38–46} 'cross-boundary coordination' (coordination across different health care settings or systems),^{11,21,25,39,41,45} and 'follow up coordination' (coordination related to appointments, medications, testing, or procedures recommended by initial visit).^{9,21,22}

Existing Survey Instruments

We identified 31 patient survey instruments with 279 specific items relevant to access to care or care coordination.^{7–9,12, 29–32,43–45,49–78} Survey instruments with items that mapped to specific domains are shown in Table 1. A document mapping individual survey items to domains allowed authors to examine survey instruments by domain and individual item (See Appendix B for sample items, full database available by request). The domains most frequently assessed by existing surveys included 'follow up coordination' most often related to follow-up testing (18 survey instruments, 35 survey items); 'primary care access' most often related to wait times to appointment dates (17 instruments, 43 items); 'cross boundary

coordination' particularly related to communication between providers from different care settings (16 instruments, 39 items); and 'relational' and 'longitudinal continuity' most often related to trust and personal relationships between patients and doctors (15 instruments total, 45 items).

Of the 11 domains, 'spatial access' was the least represented in the identified patient survey instruments. Only 8 items, from six surveys, assessed components related to 'spatial access'. There were also very few survey items assessing 'cultural access'. Of those we found, only two assessed cultural fit or comfort (whether patients felt they were treated unfairly because of race/ethnicity, and whether the doctor or nurse thought about patients' values and traditions)); the rest focused on health literacy and language barriers that can influence access to care. Of note, we did not include measures of the quality of communication between an individual provider and patient that occurred after the patient had successfully accessed care.

Preliminary Veteran Interview Themes

Our 10 interviewees were responsive to the interview questions, and provided new insights into patient experiences with VCA decisions, demonstrating the feasibility of conducting semi-structured interviews with Veterans on this topic. The most common factors interviewees identified as relevant to their decisions about and experiences with cross-system care were: wait times for appointments and tests (9 participants); distance to needed care (6 participants); burden of long distance travel when sick or injured (4 participants); patient effort required to access and coordinate care (4 participants), and to determine financial responsibility for care (5 participants); and the importance of continuity with the same provider (4 participants). Three preliminary themes emerged, all were mentioned by several interviewees and were not well represented by existing survey instruments. First was the theme that the patient's health and clinical context needed to be considered when evaluating the ease of spatial access. It was not only distance to a VHA facility that mattered, but the burden of travel when the Veteran had serious illness, a painful condition, or urgent needs. For example, a Veteran with multiple co-morbidities described the symptomatic burden of traveling long distances to receive specialty care:

"...travelling to [VA medical center 150 miles away] was a hardship to me in my condition, which is heart failure and atrial fibrillation, along with blood pressure and diabetes, to make that trip to [the VA medical center] was really taxing on me." (ID102)

Patients considered it more acceptable to travel longer distances if they were feeling well, but even 30 or 40 miles might be unacceptable if they were recovering from a procedure or had poor health in general (See Table 2 for additional quotes). Second, interviewees often mentioned the burden that falls on the patient and family to access and coordinate care across systems, and to determine financial responsibility for care. Veterans described the time and effort it took to arrange appointments across systems in those cases where processes did not work smoothly.

"I had thyroid surgery at the beginning of [month]...My outside ear nose and throat...sent a fax to the VA, at my request, saying that I needed to see an

endocrinologist ASAP. Over a month later, they still haven't made the referral." (ID104)

Coordinating care across systems involved making calls to VA and community providers to schedule follow-up tests, treatment, or to fill medications. Veterans also found dealing with the financial aspects of accessing community care (e.g. payment authorization and billing) stressful.

"...it was a little bothersome to get a bill for \$10,000, ... once we got it worked out, then I was ok with it...but ... It was one of those over the weekend things. Oh my god, if the VA doesn't pay this how am I going to pay it?" (ID106)

Third, some Veterans noticed and cared about differences in culture between the VA and community providers. Specifically, interviewees felt that clinican familiarity with the VA or military culture, and presence of fellow Veterans created an atmosphere of caring and understanding that they valued, and that drove preferences for care (see Table 2 for quote).

DISCUSSION

In our structured review of published patient surveys, we found 31 existing survey instruments that assess several domains of patient satisfaction with access to care and care coordination relevant to patients accessing care across health systems. We developed a database of survey items mapped by domain that can be used by the VHA and other systems assessing patient experiences with cross-system care. We also found preliminary indications that some types of patient concerns about cross-system care (burden of coordination, determining financial responsibility, familiar culture) were not well assessed by existing instruments, and that existing instruments do not easily capture the patients' health and clinical situation when assessing ease of accessing care.

Our review identified many existing patient survey items that can be used to evaluate pateints' decisions about and experiences with cross-system healthcare. Surveys of patients accessing out-of-system care should ensure that as many key domains related to access and coordination as possible are represented in survey items. The results of this study, and the full tool mapping all identified, relevant survey items, were shared with the VHA operations team charged with developing a new field survey assessing patient experiences with VHA-provided Community Care.

It was striking that existing survey instruments focused on *whether* patients were able to access care and *whether* care was coordinated, not on the <u>patient effort needed to achieve</u> access and care coordination. Do patients need to make multiple phone calls to obtain records to bring to another provider to ensure that informational continuity takes place, or to find out the best place to obtain a test recommended by a consultant? Is there burden related to determining financial responsibility for care? Spatial access, commonly assessed by distance from home to the site of care in performance measures, was described by patients not in absolute terms (miles) but in terms of symptomatic burden related to travel in conjunction with certain clinical circumstances. In many instances, interviewees felt their clinical situation and health status mattered to what was acceptable timely access, burden of travel, or burden of care coordination. If this concern is confirmed in further research with

patients, it will be important for surveys of patient satisfaction with cross-system care to develop and test measures of patient burden related to accessing and coordinating care (in addition to 'objective' measures such as days to appointment or percent of appointments with one usual provider), and whether the burden was acceptable to the patient given their health situation. A few identified survey items capture patient perceptions of work to obtain access: "How difficult is it for you to get to your clinic?" (MEPS) or "How long does it take you to get to {provider}[*rather than actual distance*]?" (MEPS), "How easy is it to get through to someone at your GP practice on the phone?" (GPAC), and "How often was it easy to get the care, tests, or treatment you needed?" (CAHPS-HP). Since the completion of this study, the VA began fielding a new survey, called the Survey of Healthcare Experiences of Patients - VA Community Care ('SHEP Community Care'). The SHEP Community Care survey includes questions on 1) ease of scheduling the initial Community Care visit and 2) ease of the Community Care billing process. This survey instrument could be used in the future to pilot test other new survey items if themes supporting them are confirmed by future studies with Veterans using Community Care, such as acceptability of the spatial access of VA facilities, particularly when patients are sick or in pain.

While it is not surprising that we did not find any survey instruments that specifically assess 'provider familiarity with Veteran culture' since the vast majority of surveys reviewed were designed for the general public, we believe this theme can be seen as parallel to other studies' findings that "cultural competency" eases many patients' burden of navigating healthcare systems and encounters.^{47,48} The most commonly assessed aspect of cultural access to care in existing patient surveys is access to a provider who speaks the patients' preferred language. Other aspects of cultural competency that may be important to patients considering leaving their home health care system include trust, comfort, respect, and the overall "cultural fit" with providers. Our preliminary interviews indicate that familiarity with Veteran or military culture may be an important consideration for Veterans considering care outside the VHA; if confirmed, future VHA community care surveys should consider developing and testing items related to this issue. We found two existing survey items that assessed 'cultural fit' that could be adapted for this purpose: "In the last 12 months, how often have you been treated unfairly at this provider's office because of your race or ethnicity [could substitute 'Veteran status']?" (CAHPS-CC), "Over the past 6 months, when receiving medical care for my diabetes, I was: Sure that my doctor or nurse thought about my values and my traditions when they recommended treatments to me" (PACIC).

This study should be interpreted within the context of several limitations. While efforts were made to structure a comprehensive review of peer-reviewed and non-academic literature, it is possible that there are surveys capturing patient experiences with access to care and care coordination that our search did not discover. Similarly, in this exploratory study, any themes identified by our interviews should be considered preliminary, and would need to be confirmed and expanded upon in a much larger and robust mixed-methods evaluation to be relied upon in future work. Finally, while most themes emerging from patient interviews could be applicable to patients in any healthcare system, the emphasis placed on some themes may be unique to VHA patients and their experiences with VHA-purchased Community Care. As such, the findings from this project were shared with a team that is developing a patient experience survey for patients using VA-purchased Community Care.

Healthcare systems assessing quality of access and care coordination in cross-system care should include assessment of patient's experiences, and several existing patient surveys cover domains relevant to patient experiences with access and care coordination in cross-system care. Systems should consider developing or including new measures of patient burden related to accessing and coordinating care, and determining financial responsibility for care; patients' consideration of their health situation in assessing ease of access, and patient satisfaction with cultural fit of care obtained from various healthcare systems. Future, more extensive evaluations of patient experiences with cross-system care will allow us to move further towards accurately and comprehensively measuring the aspects of access to care and coordination that patients find important.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Access and Care Coordination Domains Relevant to Cross-System Care and Related Survey Instruments

Access Domains		
Domain Name	Description	Existing Survey Instruments With Items For This Domain
Primary Care Access	Access to routine primary care that is appropriate for clinical situation and patient preferences. Includes both regularly scheduled physicals and additional primary care appointments for health problems. Includes wait time to schedule appointment, wait time to see provider once arrived, and adequate time with provider during visit.	ACES, ⁴⁹ AMGA, ⁵⁰ BRFSS, ⁵¹ CAHPS- CG, ⁵² CAHPS-HP, ⁵³ CTS, ⁵⁴ GPAQ, ⁵⁵ IHP, ⁵⁶ MEPS, ⁵⁷ NHIS, ⁵⁸ PCAS, ⁵⁹ PCAT, ⁶⁰ PEAT, ⁶¹ SHEPS, ⁶² VANCOSS ⁶³
Specialty Care Access	Access to routine specialty care that is appropriate for clinical situation and patient preferences. Includes wait time to schedule appointment, wait time to see provider once arrived, and patient effort to schedule appointment.	ACES, CAHPS-HP, CTS, IHP, NNMC, ⁶⁴ PCAT, SDQHC ⁶⁵ , SHEPS, VANCOSS
Urgent Care Access	Access to care for urgent issues that is appropriate to clinical situation and patient preferences. Includes wait time to schedule appointment and wait time to see provider once arrived.	ACES, CAHPS-CG, CAHPS-HP, CAHPS-PCMH, ⁶⁶ CTS, GPAQ, IHP, EUROPEP, ⁶⁷ MEPS, NHIS, PCAS, PCAT, QHCS ⁶⁸
Spatial Access	Geographic and transportation considerations including distance and travel time between the patient and health provider. Includes availability of other transport options such as busses, vans or relying on others to drive patient to appointments.	AMGA, BRFSS, CTS, MEPS, PCAS
Communication Access Between Visits	Communication between patient and provider(s) outside of appointments, mainly through the telephone, email or online patient portals.	ACES, AMGA, BRFSS, CAHPS-CG, CAHPS-HIT, ⁶⁹ CTS, EUROPEP, IHP, MEPS, NHIS, PCAS, PCAT, PEAT, QHCS, VANCOSS
Cultural Access	Familiarity with patient's culture. Extent to which patient and provider understand each other and there are no language barriers. Includes provider familiarity with Veteran culture and VA processes.	CAHPS-CC, ⁷⁰ CAHPS-HL, ⁷¹ CAHPS- HP, MEPS, PACIC, ⁷² PCAT, PPCMC, ⁷³ QHCS, VANCOSS
Care Coordination Domains		
Domain Name Description		Existing Survey Instruments With Items For This Domain
Longitudinal Continuity	An ongoing relationship between same provider and patient exists overtime; ongoing pattern of health care interaction that occurs in same place and the same health providers.	ACES, CAHPS-CG, CPCI ⁷⁴ , NHIS, PCAS, PCAT, PPCMC, SHEPS
Relational Continuity	Ongoing relationship between provider and patient that leads to patient trust and respect with provider.	ACES, CAHPS-CC, CAHPS-CG, CAHPS-HL, CAHPS-HP, CPCI, EUROPEP, NNMC, PCAS, PCAT, PPCMC, QHCS, SHEPS, VANCOSS, SDQHC, IPC-C ⁷⁵
Informational Continuity	Degree to which all providers caring for a patient have access to comprehensive information about the patient's previous healthcare encounters, medical conditions and records.	ACES, CAHPS-CG, CPCI, CTS, EUROPEP, IHP, PCAS, PCAT, PCCQ, ⁷⁶ PCIP, ¹ PPCMC, QHCS, SHEPS, VANCOSS
Cross-Boundary Coordination	Extent of communication and coordination between healthcare providers located in different care settings.	ACES, CAHPS-CG, CAHPS-PCMH, CPCI, CPCQ, ⁷⁷ CTS, EUROPEP, IHP, PACIC, PCAS, PCAT, PCCQ, PPCMC, QHCS, SHEPS, VANCOSS
Follow Up Coordination	Extent of coordination related to follow up appointments, medications, testing or other medical procedures.	ACES, CAHPS-HIT, CAHPS-HP, CAHPS-PCMH, CPCI, CPCQ, CTS, IHP, PACIC, PCAS, PCAT, PCSSW, ⁷⁸ PCCQ, PEAT, PPCMC, QHCS, SHEPS, VANCOSS

ACES = Ambulatory Care Experiences Survey, AMGA= American Medical Group Association Patient Satisfaction Benchmarking Program Survey, BRFSS = Behavioral Risk Factor Surveillance Survey, CAHPS-CC = Consumer assessment of Health Care Providers and Systems:

Cultural Competence, CAHPS-CG = Consumer assessment of Health Care Providers and Systems: Clinicians and Groups, CAHPS-HIT = Consumer assessment of Health Care Providers and Systems: Health Information Technology, CAHPS-HL = Consumer assessment of Health Care Providers and Systems: Health Literacy, CAHPS- HP = Consumer assessment of Health Care Providers and Systems: Health Literacy, CAHPS-HP = Consumer assessment of Health Care Providers and Systems: Patient Centered Medical Home, CPCI = Components of Primary Care Index, CPCQ = Client Perceptions of Coordination Questionnaire, CTS = Center for Studying Health System Change and their Community Tracking Survey, EUROPEP = European Society for Quality and Safety in Family Practice Survey, GPAQ = The General Practice Assessment Questionnaire, IHP = International Health Perspectives, IPC-C = Interpersonal Processes of Care, MEPS = Medical Expenditure Panel Survey, NHIS = National Center for Health Statistics National Health Interview Survey, NNMC = National Naval Medical Center Medical Home Survey, PACIC = Patient Assessment of Chronic Illness Care, PCAS = The Primary Care Assessment Survey, PCAT = Primary Care Assessment Tool, PCCQ = Patient Continuity of Care Questionnaire, PCIP = New York Primary Care Information Project, PCSSW = Primary Care Satisfaction Survey for Women, PEAT = Patient Experience Assessment Tool, PPCMC = Patient Perceived Continuity from Multiple Clinicians, QHCS = Quality of Health Care Survey, SDQHC = Survey on Disparities in Quality of Health Care, SHEPS = Survey of Healthcare Experiences of Patients, VANOCSS = Veterans Affairs National Outpatient Customer Satisfaction Survey.

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TABLE 2

Themes Not Well-Covered by Existing Survey Measures from Interviews with VCA-Eligible Veterans

Themes	Additional Participant Quotes
Spatial Access Combined with Illness Severity/Urgent Needs	"Why I did [have care in the community]? Because of the ride and everything over there and back it's 3 ½ - 4 hours. They cut that out, it leaves a pretty big hole in my groin and that's not fun to have to go all the way from [city] back here to [city] with that big hole in your crotch, you know?" (ID109) "What sense does it make to send me 90-some-odd miles up to [city], er, ah, [city] and you're going to have to send me by ambulance because I'm going to have to have to script the whole timeI can't sit up in the van or a private vehicle. I'd have to lay down." (ID108)
Patient Effort to Access, Coordinate, and Determine Financial Responsibility for	Access "I needed a knee replacement[they] gave me the option to get into the ChoiceIt took a month to realize they were sending a request to the wrong hospital"[I spent] hours on the phone, making phone callsknowing that I had the right information, then being told something different.".(ID103)
Care	Coordination "initially prior to going in [for surgery] I was told I was approved for home care and therapy close to my house, then upon discharge. I was told that I had to go to [medical center] Arbor for physical therapy I actually did call about 3 weeks ago and talked to a nurse with the program, and she said I had to get with the doctor, get another request so I can get therapy closer to my house. "(ID103) "I says I'm running out of my medicines Well how can the one hand not know what the other hand is doing One hand knew [the prescription] got scanned, the other hand says no we haven't received it."(ID108)
	Determine Financial Responsibility "I got a bill from the hospital, so I have to call someone with the program and let them know that I got this bill for \$4000 for this anaesthesia" (ID103) "I called [civilian provider] and said hey I was toold that this has already been approved for payment and is being processed, so if you don't have it you should have it sure enough I received more bills." (ID107).
Familiarity with Veteran Culture and VA Processes	"The therapy was great. I mean, the guy was, you could tell he was ex-military, or he was military." (ID103)