Extension of community healthcare outcomes in Parkinson disease (Parkinson ECHO): A feasibility study

Lee E. Neilson [a,b,*,1], Jennifer Wilhelm [b], Margaret McLain McDonnell [c], Lisa Mann [b], Jeff A. Kraakevik [a,b]

[a] Department of Neurology, Veterans Affairs Medical Center, 3710 SW US Veterans Road, P3-PADRECC, Portland, OR 97239, USA
[b] Department of Neurology, Oregon Health and Sciences University, 3181 SW Sam Jackson Parkway, Mail Code OP32, Portland, OR 97239, USA
[c] Oregon ECHO Network, Oregon Rural Practice-based Research Network, Oregon Health & Science University, Portland, OR, USA

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ABSTRACT

Background: Parkinson's disease is the second most common neurodegenerative disorder and presents with a heterogeneous group of symptoms. Managing these symptoms requires coordinated care from a neurology specialist and a primary care provider. Access to neurology care is limited for those patients with Parkinson's disease who reside in rural areas given financial and mobility constraints along with the rarity of specialty providers.

Methods: To close this gap, we developed and implemented a telehealth-based Project ECHO® (Extension for Community Healthcare Outcomes) program, "Parkinson ECHO," to provide education and support for rural clinicians and allied health members. The sessions focused on a topic within Parkinson's disease diagnosis or management followed by case discussions. We assessed the feasibility of this tele-mentoring educational offering, the favorability of this approach, and the effect it had on clinician confidence in diagnosing and treating Parkinson's disease using Likert-based surveys.

Results: Thirty-three unique participants from 13 Oregon counties and one county in the state of Washington, of whom 70 % served rural and/or medically underserved communities, participated in Parkinson ECHO. There was a 52 % dropout rate based on survey response, though session attendance was higher. Participants were overall satisfied with the format and content of Parkinson ECHO. There were improvements in knowledge and confidence in diagnosing and treating Parkinson's disease which persisted 6 months following the conclusion of the program. Unexpectedly, two participants reported convening a multidisciplinary group to discuss improvements to PD care.

Conclusion: The COVID-19 pandemic was an unexpected obstacle, but the teleconference nature permitted us to complete the program to positive effect. We found Parkinson ECHO did significantly increase participant confidence levels in diagnosing and managing Parkinson's disease.

1. Background

Parkinson's disease (PD) is a neurodegenerative disorder characterized by rigidity, slowness of movement, tremor, and gait changes [18]. The pharmacological management of these motor symptoms has become increasingly complex [2]. Less well-characterized are the non-motor symptoms, including depression, psychosis, constipation, sialorrhea and more. These non-motor symptoms are strongly associated with patient's quality of life [5]. Because of its heterogeneous presentation, PD requires multidisciplinary care. It has been shown that those patients with Parkinson's disease (PwP) who have access to specialist care have a lower risk of hospitalization for PD-related illnesses [25] and greater survival [24].

Yet access to specialist care is limited. While the supply of neurologists has remained relatively stable, the prevalence of neurologic disorders has substantially increased, leading to greater demand for

* Corresponding author at: Department of Neurology, Veterans Affairs Medical Center, 3710 SW US Veterans Road, P3-PADRECC, Portland, OR 97239, USA.
E-mail addresses: neilsole@ohsu.edu (L.E. Neilson), wilhelmj@ohsu.edu (J. Wilhelm), mclainma@ohsu.edu (M.M. McDonnell), mannli@ohsu.edu (L. Mann), kraakevi@ohsu.edu (J.A. Kraakevik).
[1] ORCID: 0000-0002-1866-0344.

neurology services. Moreover, there are great disparities between rural, medically-underserved regions and urban areas in terms of neurologist density [14]. Thus, it is perhaps unsurprising that up to 40 % of PwP in the United States do not see a neurologist [24]. This may be one reason rural living is a significant negative predictor of health-related quality of life in PD [21].

In order to close this access gap, the Parkinson Foundation (PF), Oregon Extension for Community Healthcare Outcomes (ECHO) Network (OEN), and Oregon Health and Science University (OHSU) collaborated on a feasibility study to train rural and frontier providers based on the Project ECHO® model. Project ECHO®, is a hub-and-spoke system whereby a central academic 'hub' connects with the many spokes of primary care providers and allied health professionals throughout a large geographic area. By utilizing a model where participants educate each other and actively learn, these practitioners are better prepared to deliver higher quality care to patients with complex conditions.

The Project ECHO® model rests on four pillars: 1) using technology (i.e. videoconferencing); 2) sharing of best practices; 3) case-based learning; and 4) monitoring of outcomes with regular surveys. While initially starting with hepatitis C in New Mexico [3], Project ECHO® program topics have rapidly expanded to other chronic conditions. More recently it has expanded into the realm of neurological disorders including dementia [15], epilepsy [17], and multiple sclerosis [12,1].

To our knowledge, there is no published literature or existing program applying this model to PD. However, it is well known in PD that when generalist and specialist care reinforce one another, the PD patient benefits [19]. Therefore, this Project ECHO® model holds promise for improving the quality of life of PwP with limited access to specialists. In developing and piloting this project our objectives were 1) to evaluate the feasibility of our program, 2) to evaluate the favorability of such a program; and 3) to evaluate the impact on clinician confidence in managing PD.

2. Methods

2.1. Overview and program development

The Parkinson ECHO team was multidisciplinary by design with a facilitator (RN/BSN), core faculty experts (MD, DPT), a scribe (MD), and guest speakers (MD, DPT). We devised six biweekly 1-hour sessions consisting of a welcome, roll call to facilitate name-face recognition, review of key concepts from the prior session (for sessions two through six), and a brief didactic led by a content expert (Table 1), with the remainder of the time devoted to case consultation. The sessions were augmented with online educational resources on our program website including patient education materials. These materials remain available to all registrants indefinitely, along with contact information for the expert panelists for future queries as they arise. Participants were invited to submit a recent encounter with a person with parkinsonism for shared problem solving on diagnosis and treatment options, with expert faculty facilitating. The session concluded with a brief summary of key points from the scribe, who also sent a written summary of the case recommendations one week later to reinforce learning points.

We planned for 6 biweekly sessions presented over 12 weeks; however, the COVID-19 pandemic interrupted our programming as healthcare systems shifted their focus to the evolving healthcare crisis. Thus, we completed the final two sessions after a three-month hiatus. The program was scheduled at noon on Wednesdays, i.e. over the lunch hour, to maximize participant availability. The videoconferencing platform allowed participants to see each other as well as the presentation slides and images. A chat box feature was monitored, with encouragement to verbally participate. Technical expertise and onsite support was offered if needed.

2.2. Protection of human subjects

This was submitted to the Institutional Review Board at OHSU as Study #00020683. They determined that the proposed activity is not research involving human subjects and that IRB review and approval was not required.

2.3. Recruitment

In the recruitment phase of this project, we leveraged our partnership with OEN to recruit PCPs who care for PwP and were otherwise unaffiliated with a PD center of excellence for inclusion in this program. Since this was primarily an educational offering, we did not exclude any interested party from participating.

Table 1
Curriculum topics and dates.

Date	Topic	Presenter credentials	Objectives
1/22/20	Differential diagnosis of PD and related conditions	MD (neurology)	• Recognize typical presenting features of Parkinson's Disease (PD). • Distinguish PD from potential mimickers. • Identify red flags casting doubt on the diagnosis of PD in patients with parkinsonism.
2/5/20	Treating motor and non-motor symptoms of PD	MD (neurology)	• Discuss medication options for treatment of motor symptoms of PD • Highlight considerations regarding levodopa therapy • Discuss common non-motor symptoms and treatment approach
2/19/20	Safety concerns and improving team care	DPT and RN, BSN	• Understand PD related safety issues in and out of home • Identify factors for fall risk and describe interdisciplinary treatment approaches • Describe impact of PD on driving skills and recognize at-risk drivers • Explain role of team in PD care
3/4/20	Cognitive effects of PD, including depression and anxiety	MD (psychiatry)	• Assess common neuropsychiatric symptoms (NPS) experienced by PD patients, including cognitive impairment, depression, anxiety and psychosis • Offer initial treatment for PD NPS • Understand the role PD medications may play in developing NPS • Recognize when to refer to a neurologist/psychiatrist
COVID-19 PAUSE			
6/3/20	Hospitalization and PD	MD (neurology)	• Recognize the role of PD in being hospitalized for PD and non-PD conditions • Identify drugs which should be avoided in the PD population • Identify strategies to maintain outpatient regimen • Identify PD-specific risks of hospitalization
6/17/20	Advanced stage PD and palliative care	MD (neurology)	• Demonstrate knowledge of symptomatic changes from early to late stage disease • Identify therapy options for advanced disease (pharmaceutical and non-pharmaceutical) • Understand palliative care needs • Understand how to assess caregiver burden

MD = Doctor of Medicine, DPT = Doctor of Physical Therapy, RN = Registered Nurse, BSN = Bacherlor of Science in Nursing, COVID = Coronavirus Disease.

2.4. Outcome measures

Our *primary objective* was to measure feasibility of Parkinson ECHO. Therefore, within two weeks of starting the program, all participants were sent a web-based questionnaire regarding their clinical role, years of practice, location of practice, and number of PwP seen per month. After the 6 sessions, participants were asked to complete a post-training survey. Based on the completion of the post-training survey, we calculated a dropout rate.

Secondary objectives included favorability of the program and clinician confidence measures in managing PD. Immediately after each individual session, participants were emailed a questionnaire for feedback on meeting the stated objectives, organization, relevance, use of evidence-based content and overall rating using a 5-point Likert scale. These responses formed the basis of favorability. To determine clinician confidence, participants completed questions surveying their level of comfort with diagnosing and treating PD using 5-point Likert scales prior to the program. These were then compared to responses obtained at the program's conclusion, and durability was assessed by repeating the assessment at 6 months following the conclusion of the program. To further explore the underpinnings of clinician confidence, we performed a knowledge-based assessment both pre- and post-program. Finally, we explored larger practice changes through qualitative surveys which could not be captured quantitatively.

Each survey attempt was repeated one week later to maximize the response rate. All surveys were sent by email through Research Electronic Data Capture (REDCap), a secure web application and database that is run through Oregon Clinical and Translational Research Institute (OCTRI) [11,10]. All participants were given an identification number to ensure confidentiality.

2.5. Analysis

We did not perform a power analysis or have an enrollment target given the nature of this program. Demographic data and survey completion rates were tabulated and reported. All data were reported as means with standard deviation or medians with interquartile ranges.

3. Results

Thirty-three unique participants from 13 Oregon counties and one county in the state of Washington signed up to participate (Fig. 1). Of these, 14 self-identified as prescribing healthcare providers (physicians = 6, nurse practitioners = 6, physician assistants = 2), with the remainder identified as naturopaths (1), physical therapists (2), occupational therapists (1), speech therapists (1), behavioral health specialists (3), registered nurses (3), and 'other' or 'no response' (n = 8). Seventy percent (n = 23) of participants reported serving rural and/or medically underserved populations. Participants reported seeing a wide range of PwP monthly: 1–4 PwP per month (n = 19; 73 %), 5–8 PwP per month (n = 3; 15 %), 9–12 PwP per month (n = 1; 4 %) and 13 + PwP per month (n = 2; 8 %) respectively. Of the prescribing providers, 5 reported seeing greater than 4 PwP per month (35 %).

Twenty-six participants completed the pre-survey and 16 completed the post-survey, yielding response rates of 79 % and 48 % of total registered participants, respectively. Thus, this equates to a 52 % dropout rate. For the first four sessions, we averaged 22 participants (22, 28, 16, 21 in sessions 1 through 4, respectively), whereas 7 attended session 5 and 9 attended for the sixth and final session. An online post-session survey was administered after each session using a simple 5-point Likert scale. Participants reported that the stated objectives were met, the pace and organization were very good, the content was evidence-based, and that they were overall satisfied (Table 2). Of the 16 participants who completed both the pre- and post-project surveys, we found trends in improvement in comfort levels in diagnosing and treating PD (Table 3). When re-assessed at 6 months, those trends persisted. Of the 10 completers who indicated they had prescribing power, there was improvement in comfort level in prescribing levodopa (Table 3). A separate question was posed at the 6-month follow-up asking the prescribers if they had increased confidence in their ability to treat PD with one reporting 'slightly agree', three reporting 'moderately agree', and six reporting 'strongly agree'. Confidence may come from experience or knowledge, so a knowledge-based assessment was administered to each participant. The mean score on this assessment improved from 67 % to 79 % following the conclusion of the program. Lastly, since PD is a disease requiring multidisciplinary treatment, we also surveyed the participants on familiarity with local resources, which showed improvement after the completion of Parkinson ECHO. Not only that, but 10 of the 16 respondents considered themselves 'local consultants', whereas they did not report so on the pre-program survey (Table 3).

On satisfaction measures, these participants all reported Parkinson ECHO was an effective format for learning and would recommend the program to a colleague. Supporting this quantitative data are select free-form quotes from participants indicating some examples of change in practice (Table 4). All 16 participants reported that Parkinson ECHO improved their satisfaction in treating PwPs, that learning from experiences of other primary care practices regarding PD was beneficial, and that participating in Parkinson ECHO is an effective way to enhance their clinic's expertise. Furthermore, all 16 post-survey respondents reported that they would recommend Parkinson ECHO to a colleague after their experience in the program, and 7 of this sample expressed interest in face-to-face shadowing or ongoing mentorship at the academic hub.

To assess durability, the 6-month survey asked about changes in practice seeing PwP. Two prescribers and two non-prescribers of the 16 total respondents indicated they saw at least 4 more PwP on a monthly basis than prior to the program. Encouragingly, two participants each reported they had convened a multidisciplinary group within their practice to discuss improving care and changed a policy, which led to change in patient care, and one participant led a didactic session for colleagues on PD.

4. Discussion

We were able to demonstrate that Parkinson ECHO was a feasible model of education to a wide range of health care providers, many of
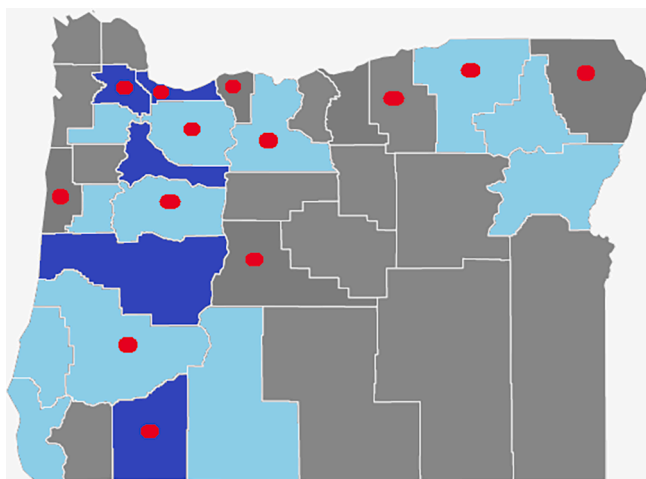

Fig. 1. Map of the state of Oregon with county boundaries delineated. One participant came from Washington state and is not depicted. Dark blue = presence of movement disorder specialist; Light blue = general neurologist; Gray = absence of neurologist; Red = Parkinson ECHO participants. (For interpretation of the references to colour in this figure legend, the reader is referred to the web version of this article.)

Table 2

Weekly survey responses.

Question	Session 1 (n = 18)	Session 2(n = 17)	Session 3 (n = 13)	Session 4 (n = 11)	Session 5 (n = 7)	Session 6(n = 6)	Average rating
Objectives met	4 (4, 5)	5 (4, 5)	5 (5, 5)	5 (4, 5)	5 (4, 5)	4.5 (4, 5)	4.75 (0.42)
Content was evidence-based	4 (4, 5)	5 (4, 5)	5 (5, 5)	5 (4, 5)	5 (4, 5)	4.5 (4, 5)	4.75 (0.42)
Pace	4 (4, 5)	5 (4, 5)	5 (5, 5)	4 (4, 5)	5 (4.5, 5)	4.5 (4, 5)	4.58 (0.49)
Organization	4.5 (4, 5)	5 (4, 5)	5 (5, 5)	5 (4.5, 5)	5 (4.5, 5)	4.5 (4, 5)	4.83 (0.26)
Relevance	4 (4, 5)	5 (4, 5)	5 (5, 5)	5 (4.5, 5)	5 (4.5, 5)	4.5 (4, 5)	4.75 (0.42)
Satisfaction	4 (4, 5)	5 (4, 5)	5 (5, 5)	5 (4.3, 5)	5 (4.3, 5)	4.5 (4, 5)	4.75 (0.42)

1 = poor, 2 = fair, 3 = good, 4 = very good, 5 = excellent; All data presented as median with interquartile range excepting the last column where means and standard deviations are reported.

Table 3

Pre-Program, Immediately Post-Program, and 6-month Post-Program Responses.

	Pre (n = 16)	Post (n = 16)	6 months Post (n = 9)
"I am __ with treating PD"	2.5 (2, 3)	3 (2, 3)	3 (2, 3)
"I am ___ with diagnosing PD"	2 (1, 2)	3 (1.8, 3)	4 (3, 4)
"I am __ with prescribing levodopa"	2.5 (1.3, 3)*	3 (3, 4)*	4 (3, 4)

1 = not at all comfortable/strongly disagree, 2 = slightly comfortable/disagree, 3 = moderately comfortable/neutral, 4 = very comfortable/agree, 5 = extremely comfortable/strongly agree; data presented as median with 1st and 3rd quartile

"I consider myself a local consultant for PD management"	2 (1, 3)	3.3 (2, 5)	4 (3.5, 4.3)
"I am familiar with PD resources in my community"	4 (2, 4)	4.6 (4, 5)	Not Available

1 = completely disagree, 2 = mostly disagree, 3 = slightly disagree, 4 = slightly agree, 5 = mostly agree, 6 = completely agree; data presented as median with 1st and 3rd quartile.

*Indicates only 14 participants answered the question as they reported having prescribing power. Both participants identified as 'behavioral health specialists'.

Table 4

Selected feedback from participants, lifted directly, outlining practice changes made as a result of participation in ECHO-PD.

- "Certainly think more about Parkinson's in my differential. Saw a patient the following day that was prescribed Abilify 5 years later and was diagnosed at that time, but had minimal symptoms after it was discontinued, and I suspect is slowly becoming more symptomatic. Started Sinemet with a follow up this week which I wouldn't have thought of before."
- "Love the resources. Will use them in my practice. I have downloaded information from the recommended Parkinson's site to give to patients."
- "Review med list for offending meds that could worsen Parkinson's."
- "Titrating melatonin up to 15 mg nice tip"
- "Space Retrieval Therapy and the U step walker are two things I am especially going to learn more about"
- "more comfortable with meds for specific [symptoms]"
- "Looking into getting a u-step for our clinic"
- "Starting Sinemet early when it's needed and appropriate"
- "[take a] better history"
- "Review med list for offending meds that could worsen Parkinson's."
- "Good practical information to empower me to attempt to treat individuals and recognize people with Parkinson's. Having a supportive team to ask questions to [in] real time is wonderful."

whom served rural and/or medically underserved populations. Overall the program was well received and providers indicated increased confidence in managing PD.

To date, there have been limited studies targeting rural-dwelling PwP. A few models have been proposed including online health communities, nurse-led clinics, asynchronous webinars, and telemedicine [20]. Online health communities do permit direct physician contact in addition to connecting with general patient resources, but patients may not feel empowered to get the specific help they need [23]. One VA-based, nurse care manager-led program in the southwest United States could serve as a model to improve areas of need for PwP [9]. Similarly effective nurse-led [8] and rehab-based [4] programs in Australia have

been shown reduce barriers to access and enhance quality of care, but the training, resources, and infrastructure required to develop and maintain such a program may limit widespread use. An even larger-scale operation in the Netherlands to disseminate national guidelines and standardize the approach to key issues in PD with the biggest effects on hospitalization and mortality is currently under investigation through a prospective trial [22,26]. Finally, telemedicine holds particular promise. One randomized controlled clinical trial compared those PwP with a stable internet connection to usual care with local physician or usual care plus four telehealth visits with a movement disorder specialist over 12 months. While they demonstrated a high completion rate and high satisfaction with the telemedicine format, there was no substantial change in quality of life measures, likely related to the high proportion of those already seeing a specialist as part of their usual care [6].

In contrast to these strategies, Parkinson ECHO, to our knowledge the first Project ECHO® with a specific and primary focus on PD, attempted to reach rural-based primary care clinicians and allied health professionals. At the time of our program, there were 258 neurologists in the state of Oregon with an active medical license in neurology, of whom 213 (83 %) practice in the six counties where a movement disorder specialist resided (Fig. 1). An additional 12 counties have a licensed neurologist that does not specialize in movement disorders. These 12 counties, and the remaining 18 counties with no neurology presence, represent a large geographic area of underserved patients. We were able to reach 10 counties with no movement disorder presence, and overall, 70 % of participants reported serving a rural population.

Despite the unplanned interruption due to COVID and the new challenges the faculty leaders and participants faced, the program was ultimately completed as planned. At first glance, feasibility may be questioned given the 52 % dropout rate based on number of registrants who completed the entire pre- and post-surveys. However, after the fourth session, we paused programming due to the COVID-19 pandemic which demanded prioritization. It is possible that the increased strain on healthcare providers increased our dropout rate. Even with this caveat, our rate is in line, or better than what has been published in similar neurology-focused Project ECHO® programs (67 % dropout rate for Lindauer et al.; 37 % for Johnson et al.; and 82 % for McDonald et al.) Therefore, not only is this format feasible, but a second Parkinson ECHO which was expanded to 10 sessions is currently underway with 30 registrants, suggesting it is sustainable. However, these offerings do often depend on grant funding or institutional support.

While it was intentional to reach primarily healthcare prescribers, given the multidisciplinary nature of PD care it was encouraging that there was interest from several allied health professionals including those in behavioral health and rehabilitation services. Participants recorded high week-to-week satisfaction and all post-survey respondents reported recommending it to their colleagues. In just a short time-frame, we were able to demonstrate improvements in self-reported confidence and comfort levels in diagnosing and treating PD. But perhaps most surprisingly, yet encouragingly, given the relatively small number of participants, two practices convened multidisciplinary groups to change practice. This point deserves greater scrutiny.

Of the 6 cases presented by outlying participants, some common themes emerged. They included medication management (n = 6),

diagnosis (n = 4), falls (n = 3), caregiver burden (n = 3), dementia (n = 3), psychosis (n = 4), sleep (n = 2), and constipation (n = 1). While each of the first four themes could be matched one-to-one with our planned didactics, the remaining non-motor symptoms proved to be a major point of focus by the participants. Given these non-motor symptoms are a strong driver of quality of life and are less often recognized as sequelae of PD outside of specialized PD centers, it would be prudent to expand this topic in future iterations. Importantly, 5 of the 6 participants reported an adjustment to their management plan; however, it is unknown if these changes led to more widespread alterations in their practice pattern.

Our pilot program does have some additional limitations. First, it is a pre– and post-study with no comparison group, so it is possible that knowledge and practice changes were due to other causes. However, our qualitative evaluation asked specifically about participants' experiences, lessons, and practice changes resulting from Parkinson ECHO to mitigate this confounder. Second, we describe self-reported provider-level outcomes, which may be subject to bias. We emphasized the pre- and post-surveys where we had complete data, but obtaining weekly responses was difficult and could be an undue burden on a busy clinician. We did not measure patient-level outcomes, but this is a common limitation in ECHO-based studies and the totality of these projects suggest a great potential for impact on improving patient outcomes [16]. Future work should explore objective provider-level outcomes, perhaps through a chart audit evaluating the AAN practice parameters for PD [7], and patient experiences associated with provider participation in Parkinson ECHO.

Finally, our study lacks long-term follow-up. It is possible that the learning effect wanes overtime. It is also possible that a 6-session Parkinson ECHO, particularly-one interrupted by a pandemic, is unable to detect changes in hospital policies or for providers to adapt their practice. However, the pandemic offered two additional strengths. First, in addition to reinforcing key concepts at the start of each session, the longer delay allowed a greater time lapse between sessions and inadvertently created a built-in spaced-repetition model of instruction [13]. Second, the prolonged delay to collecting data allowed us to capture practice changes which typically require more time to enact following the conclusion of an educational program.

5. Conclusion

Giving the disparity in outcomes, improving access to specialist care for PwP is a priority and we demonstrate that Parkinson ECHO can deliver the content effectively to rural and frontier clinicians who practice in counties without access to neurology care. Baseline preparedness and confidence in PD-related skills was low even among those motivated to attend. At the conclusion of the program, participants' self-reported confidence in diagnosing and managing PD improved significantly. There were also several specific practice changes and two participants event convened multidisciplinary groups to enact larger scale change. Considering the limitations arising from the relatively high dropout rate, this feasibility study should be followed up with replication and an assessment of objective quality metrics including review of patient records to evaluate for true practice change and connection of patients with resources.

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CRediT authorship contribution statement

Lee E. Neilson: Conceptualization, Methodology, Formal analysis, Investigation, Writing – original draft. **Jennifer Wilhelm:** Methodology, Formal analysis, Writing – review & editing. **Margaret McLain McDonnell:** Methodology, Software, Investigation, Data curation, Writing – review & editing. **Lisa Mann:** Writing – review & editing, Project administration, Funding acquisition. **Jeff A. Kraakevik:** Conceptualization, Writing – review & editing, Supervision.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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