HHS Public Access

Author manuscript

Geriatr Nurs. Author manuscript; available in PMC 2021 October 09.

Published in final edited form as:

Geriatr Nurs. 2016 ; 37(3): 200–206. doi:10.1016/j.gerinurse.2016.01.002.

Development and testing of the Dementia Symptom Management at Home (DSM-H) program: An interprofessional home health care intervention to improve the quality of life for persons with dementia and their caregivers

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Abstract

Home health care agencies are increasingly taking care of sicker, older patients with greater comorbidities. However, they are unequipped to appropriately manage these older adults, particular persons living with dementia (PLWD). We therefore developed the Dementia Symptom Management at Home (DSM-H) Program, a bundled interprofessional intervention, to improve the care confidence of providers, and quality of care delivered to PLWD and their caregivers. We implemented the DSM-H with 83 registered nurses, physical therapists, and occupational therapists. Overall, there was significant improvement in pain knowledge (5.9%) and confidence (26.5%), depression knowledge (14.8%) and confidence (36.1%), and neuropsychiatric symptom general knowledge (16.8%), intervention knowledge (20.9%), attitudes (3.4%) and confidence (27.1%) at a statistical significance of ($P < .0001$). We also found significant differences between disciplines. Overall, this disseminable program proved to be implementable and improve clinician's knowledge and confidence in caring for PLWD, with the potential to improve quality of care and quality of life, and decrease costs.

Keywords

Interprofessional; Dementia; Home health care; Alzheimer's disease; Interdisciplinary; Geriatrics; Implementation science

Introduction

Home health care (HHC) providers, including registered nurses, and physical and occupational therapists, play a major role in caring for older adults after discharge home

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from the hospital and may be essential in keeping readmission rates low. Currently, 22% of HHC patients return to the ER after discharge and 29% are readmitted.[1] Over two thirds of HHC patients are over the age of 65[2] and approximately 36% have some form of cognitive impairment[3] including dementia. This number is expected to increase significantly given the aging of the population and rise in life expectancy.[4] There are currently no treatments available to prevent or cure Alzheimer's disease and related disorders, and current symptomatic medications do not alter the disease trajectory. However, according to the Institute of Medicine, the number of providers trained to properly care for the older adult, including those with dementia and in the HHC setting is inadequate.[5]

Furthermore, the role of the interprofessional HHC team in treating persons living with dementia (PLWD) has not been clearly defined, despite the potential to identify and significantly improve the quality of life of both the PLWD and the caregiver. Dementia care can best be provided over time by an interprofessional team, defined as 'a partnership between a team of health providers and a client in a participatory collaborative and coordinated approach to shared decision making around health and social issues'.[6] Each discipline provides a distinct and complimentary set of skills to the team.[7] The registered nurse is an expert in therapeutic communication and coping strategies, as well as caregiver education and provision of pharmacologic and non-pharmacologic interventions. The occupational therapist focuses on preserving functional capacity and determining the types of compensatory strategies, assistive devices and environmental modifications that are appropriate. The physical therapist focuses on mobility, reducing risk of injuries and falls, and maximizing completion of activities of daily living. Additional skilled disciplines that can be involved in HHC though are much less frequently used as part of the interprofessional team in this setting are the social worker and speech language pathologist.

Various successful interventions have been implemented in the community using non-pharmacologic strategies, performed by single disciplines such as nurses,[8,9] occupational therapists,[10] and physical therapists[11] as well as by interprofessional teams.[12–14] However these interventions have often been created through research projects and not scaled up and integrated into existing models of care, especially those with interprofessional HHC teams.

Moreover, limited research has been performed in how to best implement evidence-based programs in HHC.[15] Given that clinicians in HHC work in the community and may spend limited time at a home office,[16] there are different challenges with both training of a workforce with members from different disciplines, and conducting an interprofessional education intervention compared to institutional settings such as hospitals and nursing homes.[17,18] Similarly, in-person training requires clinicians in HHC to leave the field and therefore productivity can be effected at a greater level than in institutional settings where they may have to leave a patient assignment and receive coverage but do not have to travel far from their practice setting. The authors have previously tested an online educational intervention in HHC on geriatric pain and depression, finding that it is feasible to implement online educational interventions in this setting.[19] However, without additional resources such as protocols, care plans, sustained mentorship and quality improvement initiatives, there is limited potential for long-term efficacy.[20,21]

The Dementia Symptom Management at Home (DSM-H) Program was designed to provide a multi-modal behavioral intervention that includes education, mentorship, and workflow changes to an interprofessional team with the intent of improving outcomes for PLWD and their caregivers. The DSM-H provides a structured way for HHC professionals to assess and manage pain and neuropsychiatric symptoms (NPS) such as agitation, aggression and psychosis in PLWD and decrease burden, stress and burnout in caregivers of PLWD. The DSM-H was developed primarily for the HHC interprofessional team of registered nurses, physical therapists, and occupational therapists, as they are the largest provider groups in HHC and provide complimentary but different care to PLWD utilizing different bases of knowledge and expertise.[7]

The aim of this study was to test the ability of the DSM-H Program to improve the knowledge, confidence, and attitudes of HHC registered nurses, physical therapists, and occupational therapists in assessing and managing pain, depression, and other NPS in PLWD. This study also sought to examine if this is a feasible resource to be used by interprofessional teams as we explore ways to improve the outcomes in PLWD and their caretakers.

Methods

Development of the DSM-H

The DSM-H was created by combining complementary elements of two interprofessional educational and training programs developed and validated by one of the authors (JEG),[22,23] the Nurses Improving Care for Healthsystems Elderly program[24] developed by the Hartford Institute for Geriatric Nursing at NYU, the NIA/NINR developed and VA implemented Resources for Enhancing Alzheimer's Caregiver Health (REACH) program,[25] and the Care of Persons with Dementia in their Environments (COPE) intervention developed by Gitlin and colleagues.[26] The content was further informed by a systematic review conducted using the Cochrane Handbook methodology,[12] and through examining current evidence-based guidelines and translating them for use in the HHC setting. Additionally, a structured communication module using the Situation-Background-Assessment-Recommendation (SBAR) technique[27] was developed in order to ensure appropriate communication between HHC clinicians and the primary care provider. This was included as research suggests that poor communication is a major stumbling block to effective and coordinated provision of HHC services.[28] Through this exhaustive process, the DSM-H was developed as an interprofessional, multimodal, training and behavior change intervention using elements as described in the next sections.

Online training

A set of interactive, online training modules for nurses, physical and occupational therapists was developed. The learning objectives were to: 1) Recognize and assess pain, depression, and other NPS in PLWD; 2) Identify, recommend, and implement evidence-based non-pharmacologic and pharmacologic treatments for these conditions; 3) Educate the primary informal caregivers on how to manage these symptoms on a day-to-day basis; 4) Perform

clear and concise communication with other home health care clinicians and primary care providers using the SBAR technique.

The training modules were broken up into 45–90 min blocks (total training time 4.5 h) for ease of learning and to limit interference with work hours. There are four modules: 1) Assessment and management of pain in the PLWD; 2) Assessment and management of depression in the PLWD; 3) Assessment and management of NPS in the PLWD; 4) Effective communication with health care professionals. Each module, included a mixture of imagery and text with narrative voiceover. The modules were interactive in that users had to click on different portions of a slide to open the content and voiceover for those areas, or to overlay additional information such as how to utilize and score a particular assessment instrument. Content-specific questions that users had to correctly answer in order to proceed were included to reinforce the learning objectives of the modules.

Clinician champions

As multiple studies have shown that education alone does not change practice,[20,21] two other components were developed for use in the DSM-H to reinforce the evidence-based practices taught in the online training program. The first was a “champions program.” The goal of this program was to develop champions to serve as clinical leads and mentors within the agency. Champions were to be identified not as experts in geriatric or palliative care, but as those with an interest in the clinical care of dementia patients, who were well-respected role models to their peers within their respective fields and organizations, analogous to the Geriatric Resource Nurse model used by the NICHE Program.[24] Champions received 14.5 h of in-person training provided by two experts in the assessment and management of dementia (AAB and JEG). This format of the training sessions included a mixture of didactic (approximately 2/3 of time) and case-based work with group discussions (approximately 1/3 of time). The content included more in-depth symptom management and communication content than what was covered in the online modules, as well as training in other areas of dementia care including advanced care planning, palliative care, and maximizing functional capacity. Champions also received training in peer mentorship skills to reinforce the online program with peers and answer questions from their peers as resources. All clinicians receiving the online training were notified of the identity and role of the champions within the online training program.

Workflow changes

To further reinforce the online training program, the third component was designed to change clinician workflow by incorporating evidence-based instruments and care plans for assessing and managing pain, depression and NPS in PLWD. Assessment instruments were provided, including the PAINAD for identifying pain,[29] the Cornell Scale for Depression in Dementia,[30] the Cohen Mansfield Agitation Inventory,[31] and the AD8 for measuring cognitive function.[32]

Study procedures

In this study, knowledge, confidence and attitudes of registered nurses, physical therapists, and occupational therapists regarding the assessment and management of pain, depression

and NPS was measured before and after completion of the online training portion of the DSM-H. Clinicians were given two months to complete the online training modules.

Measures

In order to assess knowledge, confidence and attitudes, the Dementia Symptom Knowledge Assessment was developed. This survey adapts for HHC clinicians three well-validated instruments for assessing clinician knowledge and attitudes regarding pain,[33] depression[34] and NPS[35] in PLWD, with an investigator-derived set of 4 questions using a 5-point Likert scale to determine clinician confidence in treating each of these symptoms. Because the assessment was derived from different previously validated instruments, the instrument does have varying Likert scales ranging from 5 to 7 points. The pain knowledge and attitudes sub-scales were based on a 7-point Likert scale and had 11 and 6 items respectively. The depression knowledge and attitudes sub-scales were based on a 5-point Likert scale and had 7 and 3 items respectively. The NPS knowledge and attitudes scales were based on a 7-point Likert scale and had 6 and 5 items respectively. Finally the scale examining NPS intervention knowledge was based on a 6-point Likert scale with a total of 29 items. Some items were reversed so that a higher score on each sub-scale was indicative of greater knowledge, confidence or attitudes.

Overall, there were 79 items, which on average took participants 15 min to complete with a range from 6 to 25 min. The overall Cronbach's α of the survey instrument was .9 and individual sub-scales ranged between .71 and .90, thus indicating excellent internal consistency. There were ceiling effects on several of the sub-scales, specifically the pain and depression knowledge and pain attitudes sub-scales as noted in Table 2.

Each individual who completed the training was also offered the opportunity to complete a CE form to receive CEs. The CE form included both 5-point Likert scale questions on the online modules' effectiveness as well as an open-ended question to provide qualitative feedback regarding the effectiveness and applicability of the program and any suggestions for improvement. Effectiveness statistics as measured by this form are presented. Open-ended feedback is representatively but informally presented below as feedback was generally limited to 1 or 2 sentence entries and therefore did not merit a full-fledged qualitative analysis.

Champions focus group

Separately, a semi-structured focus group with the champions 3 months post-training was conducted to ascertain their feedback about the training including their satisfaction, how well it tracked to their workflow and its applicability in this setting, as well as how they were utilized as champions in the program. This focus group was recorded and transcribed, and thematic analysis[36] utilizing Atlas.TI version 7[37] was performed. In this thematic analysis, the investigators first became familiarized with the data, then generated initial codes which were further organized into defined themes. The themes were then examined and transcripts re-coded to ensure all themes were captured and all quotes were attributed to the finalized themes.

Study sample

All non-managerial registered nurses, physical therapists and occupational therapists in a single division of a large, urban, non-profit home health agency in the Northeast were invited to participate. Of the 207 individuals eligible for the study, 191 consented to the research. Clinicians received periodic reminders to complete the training, though were not required by the agency nor did they receive any incentives other than the CE offering. An additional two clinicians from each discipline (six totals) were selected to serve as champions and separately consented; in the case of this agency the champions were clinician educators within the agency. Each participant received 4.5 h of discipline specific CEs upon completion of the training and the evaluation form. Prior to beginning the pre-training knowledge assessment, each participant was consented. The study was approved by both the NYU and clinical site Institutional Review Boards. Quantitative results for the champions are not presented here as there were fewer than 10 individuals, which would have increased risk for loss of confidentiality.

Statistical analysis

All statistical analysis was performed using SAS 9.3.[38] Internal consistency of the survey instrument was examined using Cronbach's α reliability coefficient. Coefficients between .7 and .9 were accepted as good measures of internal consistency.[39] *T*-tests were performed for numeric data and chi-square for categorical data to compare differences between those who completed the education and those who did not. Paired *t*-tests were used to compare pre-post results in completers. Overall there was very limited missing data, representing only .62% of all entries. Based on ANOVAs and Logistic Regressions, the data was found to be missing at random and multiple imputation (PROC MI) was therefore used in analyses for missing data.

Results

Overall, all 191 individuals who completed consent took the initial survey (92.3% of eligible clinicians) and began the online training modules. Of those, while all 191 completed the training modules, only 43.5% completed post-test. Characteristics of completers and non-completers can be found in Table 1. There were no significant differences in general demographic factors, however those who completed on average had more overall training in geriatrics, and occupational therapist completers on average had significantly greater experience than non-completers. There were no significant differences between completers and non-completers in terms of knowledge, confidence and attitudes as baseline, either as a whole group or in sub-group analysis by clinician type.

Knowledge, confidence and attitudes

When globally examining pre-post changes in knowledge, confidence and attitudes, there were statistically significant improvements in most of the sub-scales with the exception of pain and depression attitudes, which were non significant (see Table 2). However, when broken down by discipline, significantly different rates of knowledge, confidence and attitudes existed at baseline and the percentage change on these measures is drastically different across disciplines (see Table 3).

Clinician perception of educational outcomes

Results of the CE evaluation found high rates of satisfaction with the educational component of the DSM-H. Overall, 97% of RNs and 100% of PTs and OTs stated the education was highly applicable to their work setting and helped them care for patients. Additionally, 100% either strongly agreed or agreed that the training met the learning objectives. Responses to the open-ended question from the evaluation also were generally positive and enthusiastic with some areas specifically targeted for change. Several representative comments are listed in Fig. 1.

Champion perceptions

Two primary themes arose from the contextual analysis of the champions focus group. First, champions had two main suggestions for improving the training: 1) Increasing the use of case-based studies while reducing didactic time; and 2) Adding content on caregiver stress and burnout and communication between clinicians and the caregiver. In regard to their utilization as champions during this time, there was a mixed feeling as to whether the champions should be members of the clinician team or clinician educators. As champions, the clinician educators felt they were able to ensure new hires were oriented and mentored in care of the PLWD. However, they were not in regular communication with clinicians on the care teams, which they felt there was a barrier to mentorship of existing staff.

Discussion

While there has been a significant increase in the number of evidence-based geriatric care practices developed through rigorous science in the community based setting over the past 10 years, unlike in acute care where models of dissemination such as the NICHE program[24] have been developed, no similar vehicle has been developed for community based care. This is similar to other fields of health, such as mental health care where it has been cited as a major gap in improving care.[40] Those programs that do succeed require effective skill ascertainment or training, as well as systems of ongoing feedback and support, and cannot rely solely on a single training or provision of information.

The development of the DSM-H followed these tenets, providing care plans, assessment instruments and mentorship in addition to online training in order to effect change. Before change in practice can take effect, a systematic program for change in knowledge, confidence, and attitude in HHC clinicians and a plan for sustainability within individual HHC agencies is needed. This study demonstrated that the DSM-H provides a three-tiered intervention with relevant interprofessional education, a locally-centered Champion program, and a workflow structure that can sustain improvement in knowledge, attitudes, and confidence of HHC clinicians caring for PLWD at three months, a time when prior work has shown that training alone wears off.[12]

This research specifically showed clinicians had limited initial knowledge and confidence toward identifying and managing depression and NPS in PLWD, and modest improvements, particularly in NPS knowledge and interventions following the intervention with lesser changes noted in pain knowledge, attitudes and confidence, and depression attitudes.

Importantly, there were significant differences across disciplines both in baseline attributes and in the extent of gains. Occupational therapists showed the greatest knowledge, attitudes and confidence prior to implementation, and physical therapists the least. However, post-intervention, physical therapists improved significantly on all NPS sub-scales, and even surpassed occupational therapists in regards to the NPS intervention sub-scale, whereas the occupational therapist NPS intervention sub-scale showed a limited increase. They did however continue to have lower scores on the pain knowledge sub-scale while showing greater confidence in assessment and treatment options for pain, which is of some concern. This suggests that while there are significant opportunities to improve across disciplines, the group with the baseline greatest needs in this sample was physical therapists.

These results make empirical sense as well, as occupational therapists are often called on to develop “workarounds” to functional and cognitive deficits, and might therefore be the most familiar with management of PLWD,[41] and registered nurses, while not often trained specifically in dementia care, are trained on how to assess and manage symptoms across the lifespan.[42] While this study did not test patient or caregiver outcomes, multiple prior studies have linked improved knowledge, confidence and attitudes with improvement in patient care when the intervention is integrated into clinical routines,[43–45] and therefore the DSM-H warrants further study to examine whether that holds true in this case.

Notwithstanding the differences across clinician groups, this study showed the significant need for more training and research into how to prepare the workforce to provide evidence-based care for PLWD in the HHC setting. There has been little research on implementation science in this setting, and a significant need to improve quality for this population, similar to what Nurses Improving Care for Health System Elders began doing in hospitals over twenty years ago.[24] Given the number of PLWD living in the community is only expected to rise over the next several decades,[46] and the need to provide evidence-based, patient and caregiver centered care to this population to prevent institutionalization and hospitalization, this study illustrates the need to institute better training for clinicians caring for this population.[5] It can also become a focus for HHC agencies, some of which are struggling in the face of payment reform, new models of care, such as Accountable Care Organizations and other bundled payment and reimbursement policies under the Patient Protection and Affordable Care Act.[47] Should future research show that this or other similar programs reduce readmissions through improving patient and caregiver centered care, it could create incentives for hospitals and accountable care organizations to steer business toward those HHC agencies that focus on this population.

Limitations

There were several limitations to this study. First, this study utilized a quasi-experimental, pre-post methodology, without a control group. While all clinicians completed the modules, there was only a modest completion of the post-test, limiting the ability to know whether organizational changes or response bias affected the outcomes. Second, this study was performed at a single, large, non-profit HHC agency; future studies would require testing across multiple agencies to establish generalizability. Third, the intervention did not include other disciplines including social work, speech language pathology, and most significantly

home health aides. Social workers and speech pathologists were not included as there was not a large enough population to target in an initial study, and home health aides were excluded because they require a completely different type of intervention due lower baseline education and training, have different duties than licensed clinicians, have high turnover rates, and may have potential language barriers. Fourth, there were ceiling effects in the assessment instruments, which affected measurement of change. Fifth, this study was unable to track the utilization of the provided assessment instruments during this study as they were provided in paper format due to a freeze in changes of the electronic medical record of the HHC agency due to an impending changeover to a new system. And finally, this initial study of the DSM-H was focused on whether the intervention improved clinician knowledge, confidence and attitudes rather than change in patient and/or caregiver outcomes. Future work will therefore focus on further enhancing the DSM-H based on feedback from the clinicians to include reducing pharmacology content, increasing NPS and general dementia knowledge content, adding content on communication with caregivers, widening the scope to other disciplines, and performing a controlled trial that examines patient- and caregiver-centered outcomes.

Conclusion

This study, as an initial assessment of the interprofessional DSM-H program, showed varying improvements in the knowledge, confidence and attitudes in caring for PLWD amongst registered nurses, and physical and occupational therapists in HHC. It was implementable with limited internal resources at the agency, and was found by the clinicians to be applicable to their work and worthwhile. There is a significant need within HHC agencies to improve the care provided to PLWD, a fast growing segment of the population with specific care needs that have the potential to affect ranking on the new CMS Home Health Compare Ranking. The DSM-H may help HHC agencies to fulfill this need, and therefore requires further study to test its ability to improve patient and caregiver outcomes.

Acknowledgment

The authors would like to thank the National Palliative Care Research Center for its generous funding of this study.

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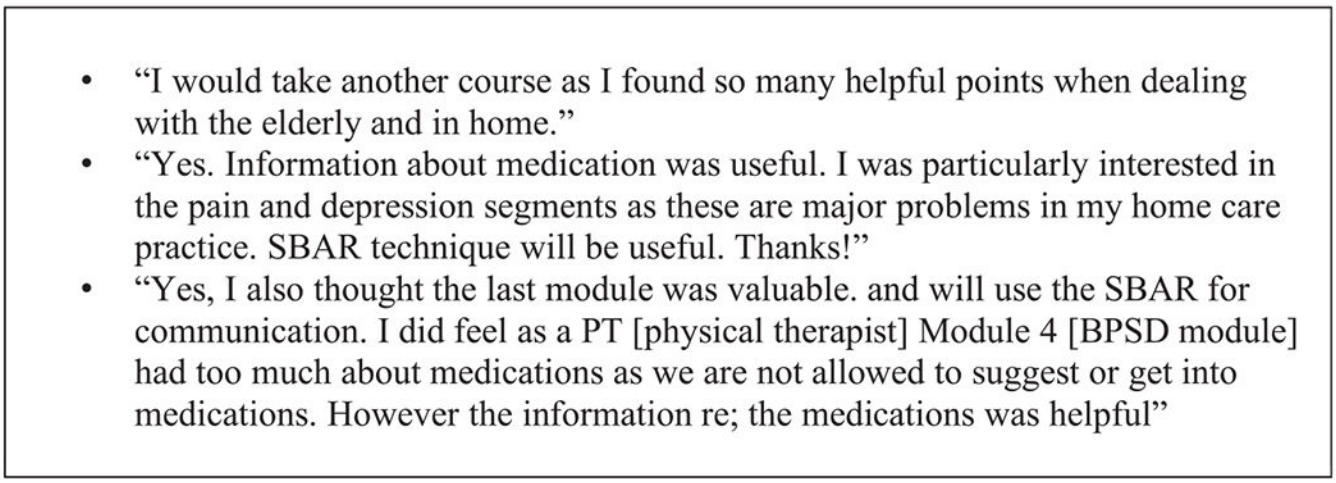

Fig. 1.
Selected qualitative evaluation comments.

Table 1

Participant characteristics.

	Completed (83)	Not completed (108)
Age	43.9 (23–83)	45.2 (24–73)
Female gender	75.4%	73.2%
Race		
Caucasian	40.2%	33.6%
African American/Black	17.1%	22.7%
Asian	32.9%	30.9%
Hispanic	6.1%	8.2%
Other	3.7%	4.6%
RN	58	85
PT	17	18
OT	8	5
Years experience		
RN	18.1 (.5–61)	19.2 (0–53)
PT	12.3 (1–26)	12.5 (.5–41)
OT *	13.1 (0–35)	10.2 (0–22)
Years experience in HHC		
RN	12.6 (.5–36)	13.3 (0–37)
PT	6.9 (0–20)	6.8 (.1–37)
OT *	8.6 (0–30)	3.2 (0–7)
Years at current agency		
RN	11.5 (.5–36)	12.1 (0–33)
PT	5.3 (0–20)	5.8 (.1–28)
OT *	8.3 (0–30)	2 (0–5)
Hours of geriatric education *	14 (2–3000)	8 (1–125)

* $P < .05$.

Table 2

Changes in knowledge, confidence, and attitudes.

Sub-scale (highest potential score)	Pre (range)	Post (range)	*P* value	Percent change
Pain knowledge (77)	42.1 (20–53)	44.59 (22–55)	<.0001	5.9%
Pain attitudes (42)	21.45 (14–30)	21.41 (11–30)	NS	−.2%
Pain confidence (20)	11.24 (5–20)	14.22 (4–20)	<.0001	26.5%
Depression knowledge (35)	21.5 (18–26)	24.69 (19–30)	<.0001	14.8%
Depression attitudes (15)	9.89 (7–13)	10.02 (7–13)	NS	1.3%
Depression confidence (20)	9.33 (4–20)	12.7 (4–20)	<.0001	36.1%
NPS knowledge (42)	24.95 (18–33)	29.13 (18–38)	<.0001	16.8%
NPS attitudes (35)	23.17 (17–33)	26.53 (17–33)	<.0001	3.4%
NPS confidence (20)	10.94 (4–20)	13.9 (4–20)	<.0001	27.1%
NPS interventions (174)	91.44 (40–144)	110.54 (49–174)	<.0001	20.9%

Table 3

Changes in knowledge, confidence and attitudes by discipline.

Sub-scale (total points)	RN			PT			OT		
	Pre (range)	Post (range)	% change	Pre (range)	Post (range)	% change	Pre (range)	Post (range)	% change
Pain knowledge (77)	43.6 (29–53)	46.0 (32–55)	5.5%**	37.0 (20–44)	39.8 (22–50)	7.6%**	42.4 (34–48)	45.3 (38–51)	6.8%*
Pain attitudes (42)	21.2 (14–30)	20.8 (11–30)	−1.9%	22.1 (15–29)	23.2 (15–30)	5.0%*	22.0 (17–26)	21.6 (20–25)	−1.8%
Pain confidence (20)	11.0 (5–20)	13.7 (4–20)	24.5%***	12.2 (7–18)	15.4 (8–20)	26.2%***	11.1 (6–20)	15.3 (11–20)	37.8%*
Depression knowledge (35)	21.3 (18–26)	24.3 (19–30)	14.1%***	21.4 (19–26)	25.6 (22–29)	19.6%***	22.8 (19–25)	25.5 (24–27)	11.8%*
Depression attitudes (15)	9.9 (7–13)	10.0 (7–13)	1.0%	9.7 (9–12)	10.2 (9–12)	5.2%	9.9 (8–12)	10 (9–11)	1.0%
Depression confidence (20)	9.5 (4–20)	12.6 (4–20)	32.6%***	9.2 (4–17)	13.0 (6–20)	41.3%**	8.5 (4–12)	13 (4–20)	52.92%*
NPS knowledge (42)	24.8 (18–33)	28.4 (18–35)	14.5%***	24.4 (19–30)	29.5 (23–37)	20.9%**	27.3 (21–32)	33.3 (31–38)	22.0%*
NPS attitudes (35)	23.8 (17–33)	26.2 (20–33)	10.1%***	20.5 (17–26)	26.8 (17–33)	30.7%***	24.1 (21–27)	28.1 (25–32)	16.6%*
NPS confidence (20)	10.9 (4–20)	13.5 (4–20)	23.9%***	10.8 (5–17)	14.4 (6–20)	33.3%**	11.9 (7–18)	15.4 (12–20)	29.4%**
NPS interventions (174)	89.9 (40–140)	107.3 (49–174)	19.4%***	89.3 (41–144)	121.5 (72–168)	36.1%*	104.9 (73–131)	111.9 (79–132)	6.7%

* <.05,

** <.001,

*** <.0001.