CLINICAL PRACTICE

Primary Palliative Care in Huntington's Disease

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ABSTRACT: Background: Palliative care practices, including communication about patient-centered goals of care and advance care planning (ACP), have the potential to enhance care throughout the course of Huntington's disease (HD) and related disorders. The goal of our project was to develop a pilot program that integrates primary palliative care practices with interdisciplinary care for HD.

Objectives: (1) To train HD team members to facilitate goals of care and ACP conversations at all stages of HD; (2) To create materials for care planning in HD focused on patient-centered goals of care and health-related quality of life; and (3) To modify clinic workflow to include goals of care and ACP discussions.

Methods: We defined planning domains to expand care planning beyond end-of-life concerns. We created a patient and family guide to advance care planning in HD. We conducted VitalTalk communications training with the HD team. We modified the interdisciplinary clinic workflow to include ACP and developed an EMR template for documentation.

Results: After communication training, more team members felt well prepared to discuss serious news (12.5% to 50%) and manage difficult conversations (25% to 62.5%). The proportion of clinic visits including advance care planning discussions increased from 12.5% to 30.6% during the pilot phase.

Conclusions: Provision of primary palliative care for HD in an interdisciplinary clinic is feasible. Integration of palliative care practices into HD specialty care requires additional training and modification of clinic operations.

Palliative care seeks to improve the quality of life of patients and families facing life-threatening illness through the prevention and relief of suffering. Palliative care is not limited by life expectancy or prognosis and can improve outcomes when delivered prior to the terminal stage of an illness. However, many patients receive palliative care late or not at all. Less than half of older adult or chronically ill individuals have completed advance directives regarding their wishes for care.

The emerging field of neuropalliative care has focused attention on the potential value of palliative care for neurodegenerative disease including movement disorders such as Parkinson's and Huntington's disease (HD).^{6–14} There is a clear consensus that provision of this care represents an unmet need.^{7,8,11,15} Over 15 years ago, a multidisciplinary task force sponsored by the Robert Wood Johnson Foundation recommended incorporation

of end-of-life care discussions into routine HD care and presented principles to guide end-of-life care. ¹⁵ However, in two recent surveys of patients with HD, only 31.3% of 242 surveyed in the Netherlands, and 38.2% of 503 in the US, had specific plans such as advance directives in place for end-of-life care. ^{16–18}

Specific models for delivery of palliative care to populations with neurologic disease vary, depending on local resources and availability of specialized palliative or neuropalliative expertise. ^{7,10,19} The primary palliative care approach was proposed in part to address an anticipated shortage of palliative care specialists. ^{20–22} In primary palliative care, practitioners incorporate core palliative care skills into their own practice, involving subspecialty palliative care clinicians for more complex issues when needed. ²²

Core palliative care practices include symptom management, involvement of patients, families and care partners in the unit of

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[Correction added on 14 November, 2022, after first online publication to update copyright line and legal agreement.]

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care, and intentional communication about complex decisions.²³ Specialty care for HD shares several features with palliative care. In both, an interdisciplinary team combines expertise in symptom management with a focus on patient, family, and care partner support.¹¹ Although there is overlap between palliative care practices and care provided by HD specialists, most clinicians who are not formally trained in palliative care lack specific training in the communication skills needed for effective conversations about goals of care.^{24–27}

We have developed a novel primary palliative care program for HD that incorporates palliative care practices into an existing interdisciplinary HD clinic, using specific communication skills to support patient-centered goals of care and quality of life, and to address advance care planning throughout the illness, not just at the end of life. ^{22,28–31} Our goal in this pilot program was to integrate primary palliative care practices with interdisciplinary care for HD through the following objectives: (1) To train HD team members to facilitate goals of care and advance care planning conversations at all stages of HD; (2) To create materials for care planning in HD focused on patient-centered goals of care and health-related quality of life; (3) To modify clinic workflow to include goals of care and advance care planning discussions.

Methods

The project team consisted of the HD program director, a movement disorders neurologist (MH); the HD program coordinator, a social worker (DM); and a neuropalliative care consultant (FD). To identify existing practices and recommendations on provision of palliative care in HD, we performed Medline searches using the following terms: Huntington's disease AND palliative care, Huntington's disease AND end of life care, and a PubMed search for Huntington's disease AND palliative care. Of the references identified, we focused on descriptions of specific programs, studies identifying utilization of palliative care or hospice services and reports assessing gaps in end-of-life care. In addition, we reviewed selected references on palliative care, particularly those describing neuropalliative care.

Previous reviews and surveys have identified HD patient and care partner needs for education, support and resources. 32–36 Patient concerns were solicited directly in the HD Quality of Life Project, in which research teams from eight HD specialty clinics surveyed over 500 patients about health-related quality of life, including end-of-life planning. 17,18,37,38 Four areas of concern were identified: legal planning, financial planning, preferences for hospice care, and preferences for care at the time of death. To extend advance care planning into stages of HD prior to the end-of-life, we incorporated these into three planning domains: personal goals and priorities; medical care; and resources and family support (Table 1).

We used functional stages based on the Total Functional Capacity score from the Unified Huntington's Disease Rating Scale to define representative care planning issues in early, middle and late stages of HD. ^{39,40} While the dominant symptoms and rate of progression in HD can vary between individuals, specific changes in function define each stage. To guide advance care planning, we identified milestones that signal transitions between HD stages. Table 2 outlines functional changes that indicate a transition to the next stage and includes examples of care planning issues. In addition to the specific motor and cognitive changes listed, mood changes (apathy, depression, irritability, disinhibition and others) can occur at any stage of the illness. ^{41,42}

Next, we identified three specific steps needed to incorporate advance care planning into our existing interdisciplinary care: (1) communication skills training; (2) education for patient and caregivers focused on care decisions in HD; and (3) modifications in clinic workflow.

(1) Communication skills. We used resources from two programs with demonstrated effectiveness in clinical trials: VitalTalk and the Serious Illness Conversation Project. ^{28–31} To equip the entire team with these skills, a VitalTalk Faculty member conducted a half day communication training session using standardized patients to demonstrate evidence-based strategies for delivering serious news, responding to emotion, defining goals, and mapping a care plan. In consultation with a health services researcher, we developed a pre/post self-evaluation survey using the Qualtrics Online Survey Software in order to assess the

TABLE 1 Advance care planning domains

Personal Goals/Priorities	Medical Care	Resources
Personal sources of support	Symptom management	 Financial resources: POA, disability, insurance, estate planning
Occupational and recreational goals	Care planning education	Counseling, pastoral care
Engagement with family and community	 Advance directives, health care POA 	In-home and respite care
• Preferences for long- term care	 Options for long-term in- home or facility care 	 Community resources, benefit programs

Note: In this model of advance care planning, personal goals and priorities provide the foundation for decision-making. At each stage of Huntington's disease, these priorities can guide choices regarding medical care and resources to support the goals and values of the individual and care partners.

TABLE 2 Care planning IN HD by stage

	S I S				
Stages	Milestones	Functional Changes	Goals/Priorities	Medical Care	Resources
EARLY					
	• Clear motor	Mild chorea, incoordination	• Identification of sources of support	• Treat mood/motor symptoms	• Establish financial POA
	symptoms Clinical diagnosis	Mild cognitive changes	Plans for delegation of household and finance management	• Establish health care POA, advance directives	Financial planning
		• Independent or requires only minor assistance	• Modifications at work		
MIDDLE					
	• Increasing disability:	 No longer able to work or drive safely 	• Support for family and community engagement	• Treat mood/motor symptoms	• Social Security disability insurance
	Development of dysphagia, worsening chorea, balance and cognition	• No longer able to perform household tasks	• Quality of life/meaning and resilience	• Modifications for safety: PT, OT, SLP	• Community resources
		• Some assistance needed with basic activities; may have increased need for supervision	Sources of emotional support	• Planning for increased care needs, site of care: home vs LTC	
LATE					
	• Assistance needed for all activities	• Limited communication	• Engagement of end-of-life resources such as hospice	• Treat mood/motor symptoms	• Site of care: home vs LTC
	Increased motor dysfunction due to chorea and other motor symptoms (rigidity, dystonia and bradykinesia)	Increased risk of aspiration and weight loss	• Support for family/care partners to prepare for endof-life	Adaptations to prevent injury	Specialty palliative or hospice care
	• Increased cognitive dysfunction	• Requires assistance to walk, or wheelchair	• Addressing anticipated loss and other emotional needs	• Modify routine to reduce behavioral issues	
		Increased behavioral symptoms		Consultation with subspecialty primary care	

Note: In this table, the milestones that indicate transition into each stage are listed, including common symptoms and functional changes. Examples from each of the three care planning domains are given for each stage.

LIVING WITH HUNTINGTON'S DISEASE: COMPREHENSIVE CARE PLANNING

NAME your goals.

DEFINE your worries.

What events are coming up for you in the next year? How about the next 10 years? We want to include these goals in your care plan. What concerns you the most? Sometimes we can help to lessen these worries by addressing them in the plan.

TOOLS TO HELP

- What Matters to Me Workbook. (from Ariadne Serious Illness Group)
- Community resources: Professional counseling, including pastoral counseling

Explore ways to ADAPT.

CREATE a safety net.

What is most difficult in your day right now? Are your symptoms getting in the way? We might be able to adjust medicines, design exercises, or suggest adaptations to help.

How would you get more help if you needed it suddenly?

If you needed more help, is there anyone depending on you who also needs a safety net? We may be able to suggest resources or help frame the problem.

TOOLS TO HELP

- HDSA: A Caregiver Guide for HD Families, Speech-Language and Swallowing Difficulties,
- Nutrition and Huntington's Disease. http://hdsa.org/shop/publications/
- HDYO (Huntington's Disease Youth Organization): provides support and education to young people (aged up to 35) impacted by Huntington's disease (HD); https://en.hdyo.org/
- Community resources: Social worker, elder or family law attorney, financial advisor, human resources, social services/social security, disability consultant or advocate

CHOOSE who would make decisions for you.

COMMUNICATE with your decision maker.

Who should speak for you if you were unable to do so yourself?

You can CHOOSE a person to fill this role. Many people with HD become unable to make complex decisions; if they haven't chosen a decision maker, then someone is chosen for them based on state law.

Talk about what is most important to you today and what you think will be most important to you in the future.

Be sure they understand your goals and priorities.

TOOLS TO HELP

- Medical power of attorney form: on-line or through elder/ family law attorney or Legal Aid
- Virginia State State Bar: Healthcare Decisions Day; https://www.vsb.org/site/public/healthcare-decisions-day
- HDSA: Advanced Directives for Huntington's Disease http://hdsa.org/shop/publications/
- Family communication guide (from Ariadne Serious Illness Group)

FIG. 1. Comprehensive care planning in HD. This guide to care planning in HD was developed for use by patients and care partners in the advance care planning process.

RESEARCH ARTICLE

effectiveness of the communication skills training.⁴³ Participants completed the survey following the training session.⁴⁴ In addition, we held formal debriefing sessions facilitated by the neuropalliative care consultant (FD) at one and 6 months following the training.

(2) Education for patient and caregivers. We created an introductory guide for patients and families to identify specific advance care planning issues in HD and provide links to additional resources (Fig. 1). We also developed a basic information sheet with treatment definitions to clarify the terms used in advance care planning. Both of these were revised based on patient and care partner feedback. Table SS1 lists the materials we developed for patients and care partners as well as selections from existing palliative care resources that provide additional information on care decisions and communicating goals and priorities.

(3) Modifications in clinic workflow. We identified changes in clinic workflow needed in order to include advance care planning. These included revisions to clinic communications with patients, reorganization of team meetings before and after clinic and additions to EMR templates. These were introduced during the pilot implementation phase (June through December 2021) and are reviewed in the Results section.

Results

In this pilot project, we collected preliminary data on the impact of communication skills training, as well as the number of documented advance care planning discussions.

Communication skills

Following the training session, eight of nine participants completed the pre/post self-evaluation survey in which they rated their understanding of palliative care and their readiness to engage in advance care planning discussions before and after their participation in the communication skills training. Over half the participants rated their understanding of palliative care as above average before they attended the session. This proportion increased following the training (62.5% to 87.5%). Similarly, 62.5% of the participants rated themselves as likely or very likely to initiate a care planning discussion before the training, which increased to 87.5% after the training. There was a more pronounced change in how participants rated their preparation for discussing serious news before and after the session (well or very well prepared; 12.5% to 50%). The proportion who rated their ability to manage difficult conversations as above average also increased from 25% to 62.5%.

We included three qualitative questions. (1) What was the main concept you took away from this session? Five comments identified recognition and response to emotion as key concepts in facilitating these conversations. (2) Is there additional information or training that would help you with conversations on goals of care? Three comments indicated that additional training would be more useful after practicing the skills in clinic. Two comments mentioned

potential benefits of collaboration with other team members in applying the skills. (3) What skill do you want to put into practice the next time you are meeting with a patient? Specific skills mentioned in individual comments included active listening, silence, and mapping a care plan. Four comments identified responding to emotion.

Modifications in clinic workflow

Pre-visit calls and letters were revised to include specific questions about care planning. A section for planning recommendations was added to patient instructions. In pre-clinic team meetings, we review use of specific communication skills, particularly setting an agenda for the visit. During the patient review, we identify care planning needs and designate a specific team member to initiate a discussion. We offer care planning materials and additional visits for those patients and families who want more information or time for discussion. We have developed pilot EMR templates to provide consistent documentation of care planning conversations. Following clinic, we review outcomes of care planning discussions and identify actions needed to implement modifications to care plans.

Advance care planning

We performed chart reviews for all HD clinic visits during the 7 months prior to and following the communication skills training to identify documented advance care planning discussions. In the pre-pilot phase prior to the skills training (November 2020–May 2021), advance care planning discussions occurred in eight of 64 encounters (12.5%) and in three additional encounters scheduled outside of clinic. During the pilot implementation phase (June through December 2021), advance care planning discussions occurred in 19 of 62 clinic encounters (30.6%) and in six dedicated care planning sessions outside of the monthly clinic. Four families requested additional telephone consultations, primarily with care partners, to follow up on the issues discussed.

Discussion

This report describes the design and pilot implementation of a strategy for providing primary palliative care in HD. To our knowledge, this is the first description of primary palliative care for Huntington's disease in which all interdisciplinary team members received formal training in communication skills and actively participate in goals of care and advance care planning discussions. In developing our program, we built on the foundation provided by the work of dedicated clinicians in both HD and palliative care, particularly neuropalliative care. We hope that sharing our experience to date will support continued development of this expanded model of practice.

Several strategies modeled on specialist palliative care have been developed to provide neuropalliative care in the outpatient setting.^{7,10,12,19} In these programs, the composition and structure of the teams vary but most include involvement of a palliative

specialist. Recommendations for providing primary palliative care have also been outlined for neurological disorders including movement disorders. An integrated neuropalliative care approach has been successfully adopted by several clinics focusing on Parkinson's disease, following recommendations proposed by patients and care partners as well as practitioners. Positive effects on quality of life have been reported in a clinical trial of specialist neuropalliative care in Parkinson's disease. However, access to integrated and specialist palliative models may be limited by the availability of subspecialty trained palliative care practitioners. Referral may entail transfer of care to a new team, which can be challenging for patients, care partners and practitioners.

In contrast, this report describes a primary palliative care approach in which all interdisciplinary team members incorporate palliative principles directly into their practice. This primary palliative care approach differs from integrated neuropalliative care models, particularly in the early introduction of advance care planning and the involvement of an expanded range of disciplines. ¹⁹ Early advance care planning has been recommended for both HD and other neurodegenerative disorders. ^{8,9,11,15,35} This is particularly important in HD, as cognitive changes may develop relatively early in the course and can limit the affected individual's ability to participate in these discussions. ⁴⁷

The original description of primary palliative care proposed several potential benefits: maintaining existing therapeutic relationships, reducing fragmentation of care, enhancing clinical skills and provider satisfaction, and improving quality of care.²² Primary palliative care for HD builds on the longitudinal model of care and expertise available in HD specialty clinics. Specialty care in HD requires symptom management for complex movement and psychiatric disorders and support for families living with multigenerational illness.^{11,32–35,48–51} HD clinicians have established relationships with patients and care partners to call on when navigating advance care planning discussion.

However, conversations about end-of-life can be difficult for patients, families, and clinicians.⁵² Most clinicians lack training in the communication skills needed for effective conversations about goals of care.²⁴⁻²⁷ In developing our program, we focused on the core palliative skill of communication. All interdisciplinary team members, representing a variety of disciplines including rehabilitative therapies, participated in communication skills training using evidence-based strategies from VitalTalk on delivering serious news, responding to emotion, defining goals, and mapping a care plan.^{28,29} Our goal was to enable each team member to begin a goals of care conversation at any time during the course of HD if the need for advance care planning was identified during their clinical assessment. During the training, practitioners were also encouraged to collaborate with other team members for support in discussion of care planning needs. After the training, more participants felt prepared to engage in these conversations and the number of advance care planning discussions increased.

Recommendations for symptom management in HD have been developed by experienced practitioners and are widely used in HD specialty clinics.^{53–65} Often, plans of care must focus on immediate safety concerns. However, these same clinical issues

also reflect functional changes due to disease progression. We defined milestones to identify transitions within disease progression that signal the need for advance care planning.^{39,40} Using these milestones, clinicians can offer anticipatory guidance to individuals and care partners before a crisis occurs. As the disease progresses, goals and priorities may change, affecting choices about care. By addressing advance care planning throughout the illness, practitioners can assist patients and care partners as they reconsider goals of care and prepare for future decisions, including timing of referral to specialist palliative or hospice care.

Our written materials for patient education and support were designed to complement these in-person discussions and to normalize care planning conversations. We created educational materials with information specific to HD to guide advance care planning from early in the illness (Fig. 1). We reviewed existing materials designed for end-of-life discussions in the setting of medical illnesses and found that many required some adaptation for in HD, in which disease progression occurs over many years. We also referenced existing resources without modification (Table SS1).

Changes to our clinic workflow were necessary to accommodate the additional time spent on exploring emotions, goals, and priorities with patients and care partners. In our interdisciplinary HD clinic, patients see practitioners from neurology, physical therapy, occupational therapy, speech language pathology, neuropsychology and social work, either in individual appointments on site or in telemedicine appointments that include the entire team. This intensive clinic experience can be emotionally and cognitively demanding for patients, care partners and clinicians, leaving little additional time or energy for complex emotional discussions. Therefore, identifying opportunities for care planning and ordering the priorities of the clinic visit during the preclinic team meeting was essential. By identifying issues ahead of time and developing a plan to address them, we were able to increase the number of advance care planning discussions during clinic. In addition, we scheduled dedicated visits to provide additional time for complex decision-making when necessary.

Both the pilot and pre-pilot phases took place during the early years of the COVID pandemic, when telemedicine use increased substantially. As reported previously, our team has conducted telemedicine visits routinely for over 20 years with equivalent recommendations resulting from both visit types. Therefore our team was familiar with conducting remote visits and did not experience this as a barrier. However, during the pilot phase we recognized that advance care discussions via telemedicine benefitted from more strategic planning than needed for discussions conducted in person. Uncertainty about team member roles and responsibilities could disrupt the flow of conversation and required clarification prior to starting the visit. Inadequate privacy, especially in the facility setting where patients have less control over their surroundings, sometimes resulted in postponing a goals of care discussion.

The issues we have encountered during implementation overlap with those reported in developing neuropalliative care clinics.¹⁹ While the specifics of clinic organization vary among programs, there is a high degree of consensus on principles that can guide implementation of palliative care in neurodegenerative disorders which are outlined in Table SS2. 8,9,12–14 To plan for future development of our primary palliative care approach, we are collaborating with a health services researcher in a formal quality improvement process. The core team for quality improvement includes the program coordinator, primary HD team occupational therapist and the health services research specialist. This team will lead changes in work flow, define specific outcomes and design evaluations to assess the impact of the program, in consultation with the interdisciplinary HD team.

To guide the next steps in implementation, we are using a detailed logic model to build on our experience in the pilot phase.⁶⁷ This model is a specific planning tool that provides a structure to assess success in accomplishing the program's intended outcomes in a quality improvement process. We have defined specific outcomes in four broad areas following recommendations for assessment from both primary palliative care and integrated neuropalliative care approaches.^{7,10,19,22,46} These include: (1) advance care planning outcomes such as completion of advance directives, care plan modifications and functional outcomes; (2) referrals to specialist palliative care or hospice and communication with specialist providers; (3) impact on quality of life for both patients and care partners, as well as their perceptions of clinic experience; and (4) provider perception of clinic experience and further assessment of skills development.

Our preliminary results support the potential benefit of a primary palliative care approach to increase engagement in advance care planning. Additional informal observations suggest that this approach may benefit patients, care partners and clinicians in other ways. During the pilot phase, the HD program coordinator received unsolicited positive feedback from several families on the value of these care planning conversations. In addition, team members spontaneously reported benefits of the Vital Talk tools in other settings and noted increased collaboration among team members during the clinic. We have identified existing survey tools to assess several of these areas and have conducted an interactive needs assessment with providers to obtain input on additional steps for implementation. In order to continue to adapt our design, we will use ongoing formative evaluation activities from a model on stages of change.⁶⁸

As we continue with these changes in practice, further modifications will be based on assessment of outcomes for patients and care partners as well as clinicians. Positive effects on quality of life have been reported in a clinical trial of specialist neuropalliative care in Parkinson's disease. We anticipate that a primary palliative care approach will have a similar impact in Huntington's disease.

Conclusions

In this report, we have described the initial steps in developing a primary palliative care approach to interdisciplinary HD care. We equipped our team with formal communication skills training, and provide materials on advance care planning to patients and care partners, including some which we developed or adapted specifically for HD. We have modified our clinic

workflow to identify indicators for advance care planning and to incorporate these discussions. In adding these elements to our existing interdisciplinary expertise in HD symptom management, we have laid the foundation for a program that integrates primary palliative care practices with interdisciplinary care for HD.

Primary palliative care offers a number of potential advantages as a strategy to provide comprehensive care for HD. Advance care planning can be introduced early in the illness and modified as the disease progresses. The entire interdisciplinary team can contribute expertise in HD symptom management to the advance care plans. Support for patient and care partners in these discussions may be enhanced by the long-term relationships many families have with HD specialty programs.

From our experience to date, we have drawn several conclusions:

- 1. Primary palliative care for HD is feasible in an outpatient interdisciplinary clinic setting and has potential benefits for patients, care partners and clinicians.
- 2. A primary palliative approach to care for HD integrates the perspectives of multiple disciplines from both HD specialty care and palliative care.
- Intentional communication with patients and care partners about advance care planning helps align the efforts of the entire interdisciplinary team with the priorities of those living with HD.
- 4. Successful implementation of primary palliative care in an interdisciplinary clinic requires communication skills training for clinicians, education and psychosocial support for patients and care partners, and modification of clinic operations.

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Author Roles

(1) Research project: A. Conception, B. Organization, C. Execution; (2) Statistical Analysis: A. Design, B. Execution,

C. Review and Critique; (3) Manuscript Preparation: A. Writing of the first draft, B. Review and Critique.

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Disclosures

Ethical Compliance Statement: Prior to initiating the project, the proposal was reviewed by the University of Virginia Institutional Review Board for Health Sciences Research and determined to be a quality improvement project and not to represent research on human subjects. Informed patient consent was not necessary for this work. We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this work is consistent with those guidelines.

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Supporting Information

Supporting information may be found in the online version of this article.

Table S1. This table lists materials developed during this project for provider training and for patient and care partner education. Additional outside resources providing information on care planning are also listed.

Table S2. This table lists aspects of palliative care that patients, care partners and practitioners have identified as central to the provision of palliative care in neurodegenerative disorders. 8,9,12–14