



# Increasing Essential Palliative Care Delivery within an Outpatient Multidisciplinary Amyotrophic Lateral Sclerosis (ALS) Clinic

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## Statement of the Problem

- Amyotrophic Lateral Sclerosis (ALS) is an incurable progressive neurodegenerative disease leading to death within 2-5 years.
- Care delivered in a specialized ALS multidisciplinary clinic (MDC) extends survival and improves quality of life but varies nationwide in implementation, makeup, and palliative care (PC) integration.
- PC referral guidelines did not exist for Kaiser Permanente of Washington (KPWA) ALS patients.
- Early PC integration can assist in goals of care discussions, improve family caregiver support, and facilitate discussion of future hospice services.

## Background/Literature Review

Early feasibility and descriptive studies integrating Specialty PC visits with ALS MDC demonstrate more focus on Advance Care Planning, decision-making around care transitions, psycho-spiritual concerns, than physical symptom management.<sup>1-3</sup>

## Purpose/Objectives

This Quality Improvement project's purpose is to improve primary PC knowledge in ALS MDC team members. Objectives:

1. Provide primary PC education and tools to ALS MDC providers
2. Guide ALS providers in normalizing early integration of PC services into MDC to patients and caregivers.
3. Assess completion of ACP documents and hospice referrals.

## Methods

**Sample/Setting:** KPWA ALS Clinic, ½ day monthly meetings with IDT meetings (Neurology, Pulmonology, Physical Medicine & Rehabilitation MDs, RN Coordinator, PT, OT, ST, Nutritionist, SW, ALS Association representative)

**Timeline:** July 2021-January 2023

**QI Project:**

- Three 10-minute educational interventions + resource dissemination
- Participation in IDT conferences
- SPC attending provider involved during clinic visits
- Patient/family education about PC
- Feedback gathered

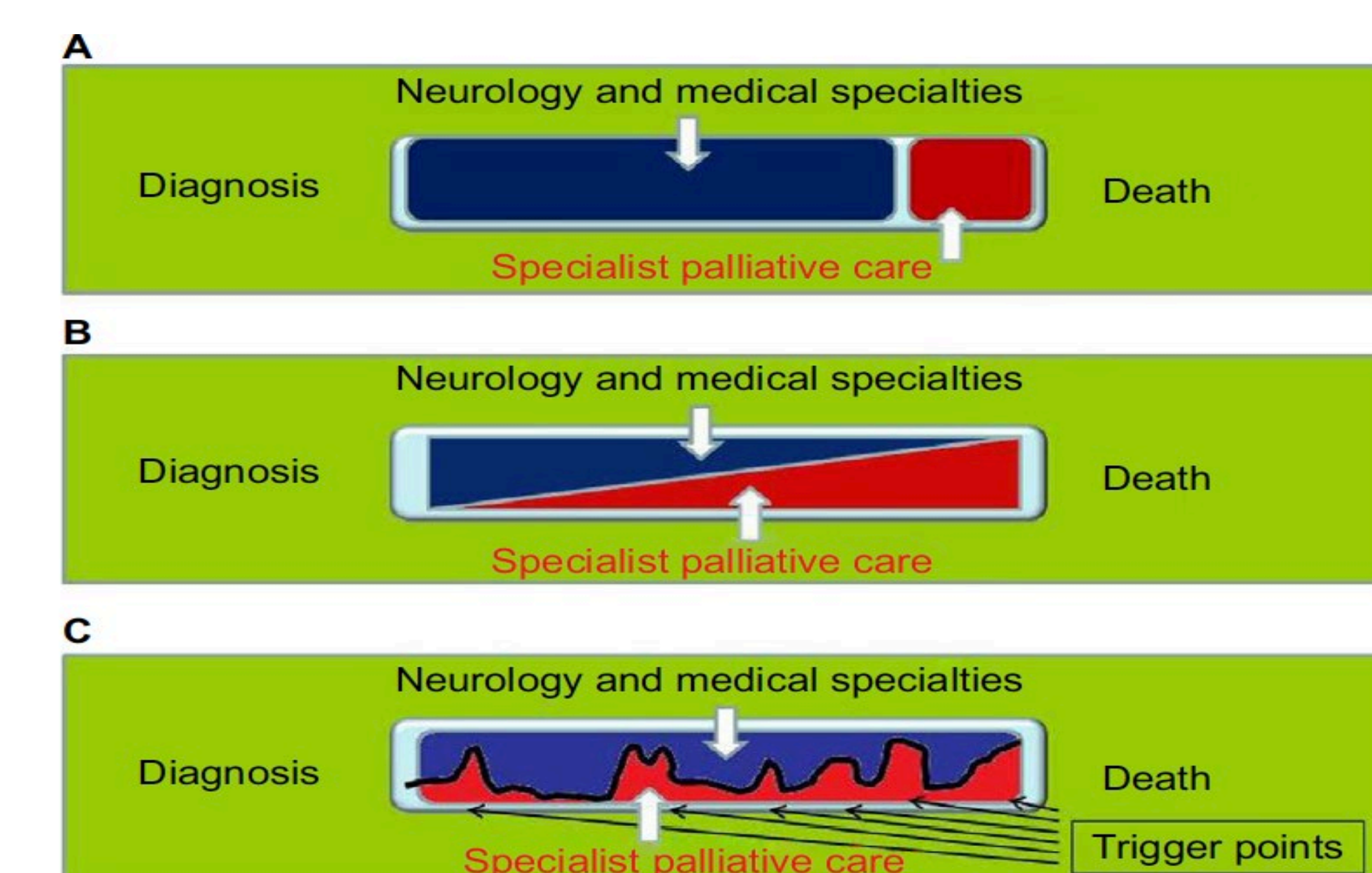
## Results

- 35 patients with ALS received MDC care
- 17 patients died; 12 received hospice services
- Average length of hospice stay = 76 days (3-257 days)
- 49% and 60% completed durable healthcare power of attorney (DPOA) and POLST forms, respectively.
- Among patients who died, 53% and 65% completed DPOA and POLST forms, respectively.

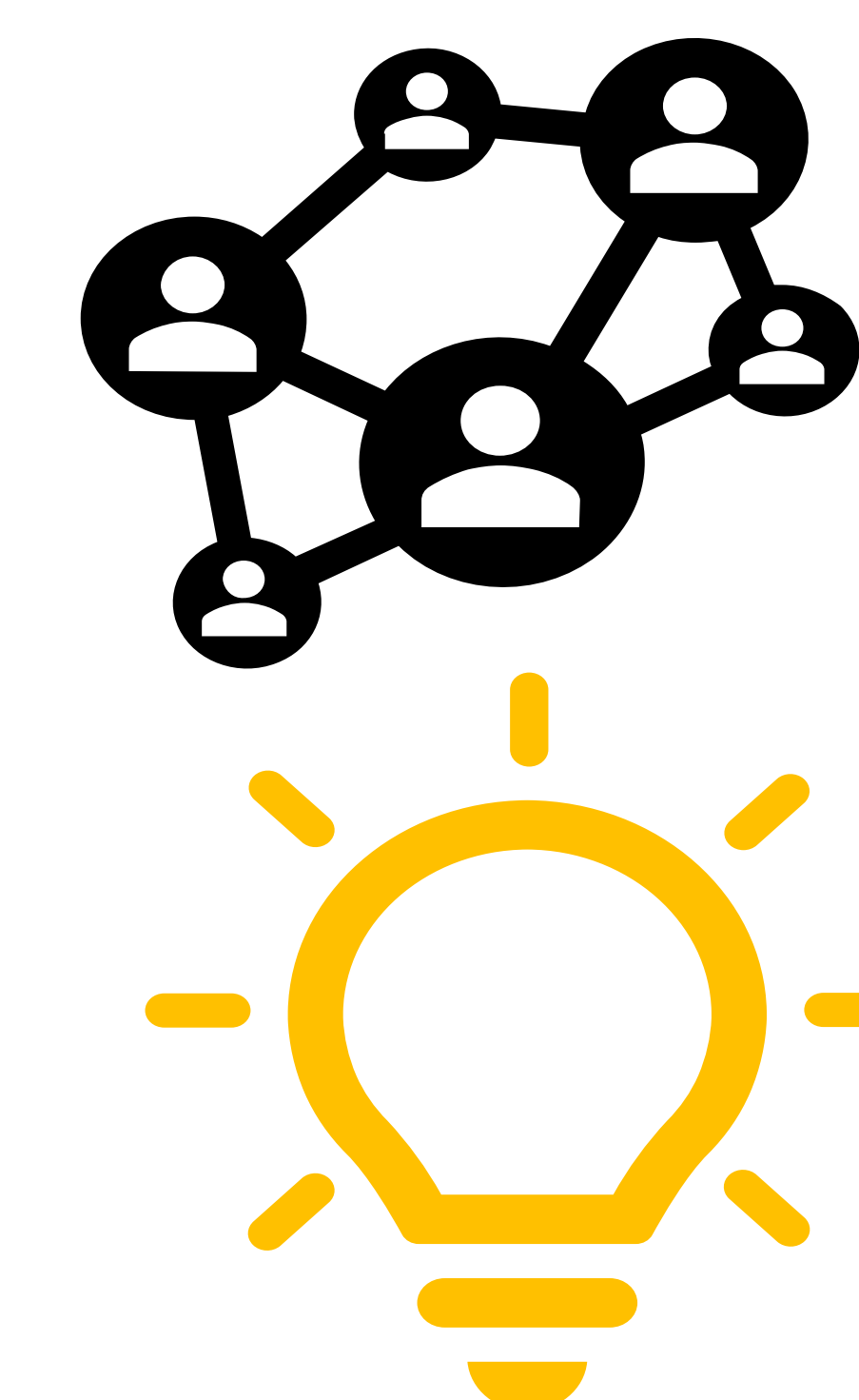


## Conclusions/Implications

- Educational interventions were well received.
- Introductory effort to expand SPC services within neuro disease patient population via ALS MDC group
- SPC attending rapidly increased perceived support
- Future directions include tailoring warm hand-offs between ALS and SPC teams.



Hogden 2017;10 J Multidisciplinary Healthcare<sup>4</sup>



## Limitations

- Small homogenous population limited to KP insured
- Challenges:
  - Difficulty navigating initial narrow footprint for SPC referrals impacted ability to meet patients/support needs early
  - Changing experienced provider practice patterns
  - Decreased MDC time to attend education

## Acknowledgements/References

Mentors: Melissa C. Palmer, LCSW, ACHP-SW, APHSW-C JD

Regina M. Fink, PhD, APRN

Thanks: Edward C. Tay, MD; Luci Wilcox, RN; HPM leadership,

Ran Huo, MD; Ali M. Mendelson, MD

References:

1. Brizzi K, Paganoni S, Zehm A, De Marchi F, Berry JD. Integration of a palliative care specialist in an amyotrophic lateral sclerosis clinic: Observations from one center. *Muscle Nerve*. 2019;60(2):137-140. doi:10.1002/mus.26607
2. Hafer J, Jensen S, Wiedau-Pazos M, Mehta AK. Assessment of feasibility and utility of universal referral to specialty palliative care in a multidisciplinary amyotrophic lateral sclerosis clinic: A cohort study. *Muscle Nerve*. 2021;63(6):818-823. doi:10.1002/mus.27194
3. Phillips JN, Besbris J, Foster LA, Kramer NM, Maier S, Mehta AK. Models of outpatient neuropsychiatric care for patients with amyotrophic lateral sclerosis. *Neurology*. 2020;95(17):782-788. doi:10.1212/wnl.00000000000010831
4. Hogden A, Foley G, Henderson RD, James N, Aoun SM. Amyotrophic lateral sclerosis: improving care with a multidisciplinary approach. *J Multidiscip Healthc*. 2017;10:205-215. Published 2017 May 19. doi:10.2147/JMDH.S134992