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When Patients Don't Come to Dialysis

Heartland Kidney Network receives many calls from facility staff regarding patients who don't come for treatment for days or weeks at a time. Some callers ask if it is okay to discharge a patient who hasn't been in for a treatment for 30 days or longer.

The protection of patient rights is the priority of the Network and we are monitoring for any unintended consequences for the patients due to the new payment rules. However, we want to acknowledge the concern we are hearing from facilities about how to balance a patient's right to refuse any aspect of the treatment plan with facility concerns about the Quality Incentive Program (QIP) that began January 1, 2012. Since the QIP ties reimbursement to patient outcomes, we wish to provide a review of the Conditions for Coverage to ensure that patients' rights and the facility's standing with CMS are protected. This resource will also offer steps to take when a patient does not come to dialysis.

As you know, patients have the right to refuse any aspect of their treatment plan. This right includes missing treatments. V456 in the CMS Interpretive Guidance states:

“The patient has the right to be informed about and participate, if desired, in all aspects of his or her care, and *be informed of the right to refuse treatment*, to discontinue treatment, and to refuse to participate in experimental research.” Additionally, the Interpretive Guidance indicates at V559 that the Interdisciplinary Team “must recognize each patient has the right to choose less than optimal care *when the patient determines* optimal care would negatively impact his/her quality of life.”

Thus, **patients cannot be discharged from the dialysis facility for non-adherence.** Instead, the Interdisciplinary Team is required to “focus on identifying the potential causes of the non-adherence and addressing those causes.”

Patients skip treatments for a variety of reasons such as:

- Dialysis adjustment issues, including:
 - Disliking dialysis
 - Exercising the right to self-determination
 - Not believing that dialysis is truly needed
- Avoidance of pain, discomfort or embarrassing situation (e.g., when patient has diarrhea)
- Life tasks/family obligations
- Transportation problems
- Conflict with staff
- Mental health issues
- Substance abuse

Understanding why a patient is missing treatments is the first step to addressing the issue, thus a re-assessment should be initiated to determine the root cause.

Assessment

It is the responsibility of the facility to assess the barriers to treatment attendance and address those barriers with the patient. Designating the patient who chronically misses treatments as “unstable” and revising the patient’s care plan would be a way to engage the entire IDT in a focused effort to identify barriers, plan interventions that address the barriers, and monitor and document outcomes. “Any member of the IDT, including the patient, may document why goals are not met or cannot be met” (V559).

There are times when staff members believe a patient is missing treatments “all the time” when, in reality, the number of missed treatments by a patient in a week or month is relatively small. Quantifying the number of missed treatments and identifying any pattern to the days of the week that treatments are missed will help determine the extent of the problem. This may also be a useful education tool for the patient.

Staff behavior can negatively influence patient adherence behavior. Staff members sometimes make the mistake of chastising a patient each and every time the patient shows up late for treatment or comes back after missing one or more treatments in a row. This is usually not an effective intervention for addressing adherence issues and is likely to create conflict between patient and staff. It may have the opposite effect on the patient’s behavior than what was intended. Patients tell us that they believe staff doesn’t care about them and whether they come to treatment or not; rather, they feel that the staff is more concerned about having an empty chair and a missed treatment they can’t bill for. Has any patient said this to you? If so, you may want to examine staff communication and facility processes for dealing with patient adherence.

Some patients just aren’t ready to commit to ongoing dialysis. Some patients believe that they don’t need dialysis and have enough residual renal function to support their misperception about their health status. They show up once in a while and then disappear for days or weeks. Others may stop showing up altogether. Education falls on deaf ears and phone calls and welfare checks are considered harassment by the patient.

Some patients may not know how to tell you directly that they want to stop treatment. Other patients are clear that they don’t want to come to treatment but the facility doesn’t agree with the patient’s decision, so staff keep calling the patient and sending out the police. Therefore, it is important that there is a discussion with the patient that discontinuing treatment is an option, what it means, and that end-of-life care can be arranged for them. Patients also need to know that if they make the decision to stop treatment now, they can change their minds and return to dialysis at your center in the future.

Depending on the underlying barriers to adherence to treatment attendance, you may want to consider negotiating with the patient a goal in the plan of care to increase attendance by one more treatment a month, re-evaluate, and if patient is successful try to negotiate attending two more treatments the following month, etc.

Interventions

Below are interventions for the patient who chronically misses treatments and is unresponsive to individualized interventions to decrease the number of missed treatments:

- If a patient chronically no calls/no shows, consider not setting up the machine until the patient arrives. The patient will then have to wait until the machine is ready to be used and treatment time will be cut in order to minimize disruption to other patients' treatment schedules.
- Move the patient to the last shift of the day in order to minimize disruption to facility operations.
- Involve the patient's nephrologist in attempts to re-engage the patient in his care.
- Send a letter to the patient that focuses on your concerns about him and his safety and your desire to meet with the patient. The letter should not include a demand that the patient receive a treatment in order to have a meeting. Examples of goals for meeting with the patient include assessing a catheter, reassessing barriers to treatment adherence, drawing blood to update lab results and possibly the patient's dialysis prescription, talking with the patient about discontinuing treatment, and planning for end-of-life care, if appropriate.
- If you are unable to contact the patient by phone (no working phone number; no answer to voice messages; no emergency contact information), call police for welfare check and document outcome. If the patient is a home patient, schedule a home visit by the PD nurse and social worker in order to assess the patient.
- Contact Adult Protective Services if the patient is a vulnerable adult whose competency is questioned or who is known to be incompetent to make his own health care decisions and there is no known power of attorney or power of attorney is unavailable or refuses to be involved.
- Utilize emergency psychiatric services, including hospitalization for evaluation and treatment, if there is concern for immediate patient safety and patient has known or suspected mental illness.
- Thoroughly document all interventions and results. V767 states "Facilities are not penalized if a patient or patients do not reach the expected targets if the plan of care developed by the IDT is individualized, addresses barriers to meeting the targets, and has been implemented and revised as indicated".

Please do not hesitate to call the Network if you would like a case consultation.

CMS Frequently Asked Questions

CMS has provided some additional guidance in regard to a patient who does not come for an extended period.

V767	Involuntary Discharge: May a facility involuntarily discharge a patient who does not come for treatment for an extended period, for example, 3-4 weeks?	The regulations specifically address the involuntary discharge process in an effort to reduce its occurrence. Facilities should work to avoid the need to involuntarily discharge any patient. In the situation described, a better resolution would be if the facility sent the patient a certified letter expressing concern about their absence from treatment and a willingness to talk with the patient about why s/he is not coming for treatment. In the letter, they could tell the patient that s/he has the right to discontinue treatment, that doing so will likely result in his/her death, and that if s/he chooses to resume dialysis, to call to let the facility know this so the facility can schedule the dialysis treatment. The facility should provide names and phone numbers of key people s/he could talk with including the physician, social worker, and nurse manager or facility administrator. If the patient is unable to be reached, or does not respond to these efforts, the patient may be voluntarily discharged, as the patient has chosen to discontinue treatment.
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CMS Version 1.3, ESRD Conditions for Coverage, Frequently Asked Questions.
SC11-13-02_End_Stage_Renal_Disease_Updated_of_Frequently_Asked_Questions_attach1.doc.x

In a case where the above is appropriate, the Heartland Kidney Network would recommend that a reasonable deadline (30 days) be provided to the patient.

- Contact with the Network regarding the situation and provide documentation of the facility prior to indicating the patient has chosen to discontinue treatment.
- It should be noted and the patient should be informed that if they chose to discontinue and their Medicare coverage is only due to ESRD than their Medicare coverage would be terminated.

The Patient Services Department has developed the attached checklist for working with patients with this type of non-adherence which should be used in conjunction with discussions with Network staff.

Please contact the Patient Services Department to inform the Network of any such situation.

Thank you to Network 15 for sharing their resource “When Patients Don’t Come to Dialysis”.

Facility Checklist

The Network is providing this checklist as a guide to ensure that proper actions are being taken before a patient is deemed “Lost to Follow Up” or considering discontinuing treatment. Contacting the Network to share your concerns should be completed as part of the checklist.

The definition of “**Lost to Follow Up**” is: Patient stopped attending dialysis and his/her *whereabouts are unknown*. The facility should make every effort to locate the patient. **This event should be rarely used.**

- Contact the Network regarding the concern
- Consider the patient as “unstable” and complete a re-assessment, following the guidelines per the Conditions for Coverage
- Discuss a new Plan of Care based on the re-assessment during your Interdisciplinary Team meeting
- Include the patient – offer a phone conference if patient won't come in.
- Contact the patient to determine why he/she has not presented for treatment.
- Attempt to reach by phone
- Letter(s) sent (certified) to reach patient
The letter should express concern about their absence from treatment and a willingness to talk with the patient about why s/he is not coming for treatment. (Offer a meeting to discuss without requiring them to come in for a treatment. In the letter, they could tell the patient that s/he has the right to discontinue treatment, that doing so will likely result in his/her death, and that if s/he chooses to resume dialysis, to call to let the facility know this so the facility can schedule the dialysis treatment. The facility should provide names and phone numbers of key people s/he could talk with including the physician, social worker, and nurse manager or facility administrator. In addition, the patient should be notified that if they have Medicare coverage due to their ESRD than they will lose their Medicare coverage if they discontinue.) A review of options if the patient chooses to discontinue (ex. Hospice) should be included as well.
- Contact the patient's alternate emergency contact(s).
- Contact the police (do a wellness check)
- Contact the acute facility/hospital where patient most recently was
- Contact the local resources (ie. Division of Aging)
- Document all efforts to reach the patient
- Fax documentation the Network- Attn: Patient Services 816-880-9088. **Do not send patient information via email.**

The Patient Event Definitions and Business Rules state the definition of “**Discontinue**” is: Patient discontinues dialysis after the decision to permanently stop dialysis has been specifically articulated.

1. This event is only used when a patient, family, or legal designee communicates the decision to discontinue dialysis with the expectation that death will soon follow.
2. Facility is expected to follow the patient for 30 days following a discontinuation from treatment, and must submit form CMS-2746 form for patient if death occurs within 30 days.

* It is expected that if the patient returns or is “found” at any time that the facility should resume treatment at the facility when/if they are medically stable for outpatient treatment.