Objectives

• Understand the transplant workup process.
• Identify common psychosocial barriers to the referral and transplant workup process.
• Identify the recent changes in the Kidney Transplant Allocation System and how that impacts patients on the waiting list for a kidney.
• Provide a framework to improve collaborative interventions by transplant and dialysis social workers to address psychosocial barriers and help improve patient outcomes.

Understanding the Transplant Work-up Process

• Every patient referred for transplant meets with the transplant team for an evaluation.

Purpose of the Transplant Social Work Evaluation

• Assess the psychosocial candidacy of the patient
• Identify any psychosocial barriers
• Identify strengths and resources of the patient
Purpose of the Transplant Social Work Evaluation

- Caregiver support for an extended period of time post-transplant
- Current adherence to medical regimen
- Ability/willingness to follow a strict, long-term post-transplant protocol
- Financial resources and long-term access to medications

The transplant social worker then makes a recommendation to the transplant team on the patient’s readiness for transplant from a psychosocial perspective.

Transplant Social Worker Interventions

- Motivational interviewing
- Symptom Targeted Intervention (STI)
- Assessment of health literacy
- Brief counseling
- Case management services

Purpose of the Transplant Social Work Evaluation

- Realistic expectations and understanding including risks and complications
- Mental health/substance abuse issues
- Long term disability or rehabilitation issues

Formulate a care plan to address psychosocial barriers

Monitor adherence

Referrals to outside providers such as mental health or substance abuse treatment

Dialysis Social Work Role & Interventions

- Counseling
  - Adjustment to chronic disease
  - Individualized Patient Care Plans & Goals
  - Adherence
  - Mental Health/CD/Support System Evaluation & Intervention
  - Quality of Life
  - Symptom Targeted Intervention
  - Motivational Interviewing
- Education & Advocacy
  - Health Literacy
  - Advance Directives
  - Patient Rights & Responsibilities
  - Access to Community Resources
  - Modality
  - Vocational Rehab
**Dialysis: CfC Patient Rights**

- Educating patients on transplant as a modality option
  
  - The 2008 Centers for Medicare and Medicaid Services Conditions for Coverage (CfC) requires that every patient be educated on transplant.

**Dialysis: CfC Patient Rights**

- Why is transplant education important for dialysis patients?

  According to research study, *Improving Transplant Education in the Dialysis Setting: The Explore Transplant Initiative*...

  "Although dialysis is life saving, the survival, quality-of-life, and cost-saving benefits of receiving a transplant over remaining on lifetime dialysis have been clearly established. After 5 years, only 33% of dialysis patients are still living, compared with 70% to 80% of patients who receive a deceased or living-donor transplant."

  Source: Explore Transplant Initiative by Waterman et al, 2010

**Dialysis: CfC Patient Rights**

- How do we accomplish transplant education and meet CMS requirements?

  - Recognize that dialysis IDT is not the ultimate decision maker as to whether a patient is a "suitable" candidate for transplant; rather it’s dialysis team’s responsibility for ensuring that patients are:
    1. Aware of transplant as an option
    2. Knowledgeable about the transplant selection criteria
    3. Knowledgeable about the transplant referral process
    4. Ensure that education on transplant has been documented in patient assessment and plan of care
    5. Communication and collaboration with transplant social worker

**Dialysis: CfC Patient Rights**

<table>
<thead>
<tr>
<th>Centers for Medicare &amp; Medicaid Conditions for Coverage</th>
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<tbody>
<tr>
<td>V468 (7) Patients have the right to be informed about all treatment modalities and settings, including but not limited to, transplantation, home dialysis modalities, and in-center hemodialysis.</td>
</tr>
<tr>
<td>V513 (10) Evaluation of suitability for transplant referral, based on criteria developed by the program transplantation center and its surgeon(s). If the patient is not suitable for transplant referral, the basis for non-referral must be documented in the patient's medical record.</td>
</tr>
</tbody>
</table>
| V554 (ii) Transplantation Status. When the patient is a transplant referral candidate, the interdisciplinary team must develop plans for pursuing transplantation. The patient’s plan of care must include documentation of:
  - (A) Risk for transplantation if the patient accepts the transplant referral;
  - (B) Patient’s decision, if the patient is a transplantation referral candidate but declines the transplant referral; and
  - (C) Reasons for the patient’s non-referral as a transplantation candidate. |
| V561 (c) Standard: Transplantation referral tracking. The interdisciplinary team must:
  - (1) Track the results of each kidney transplant center referral;
  - (2) Communicate with the transplant center regarding patient transplant status at least annually, and when there is a change in candidate status. |
| V562 (d) Standard: Patient education and training. The patient care plan must include, as applicable, education and training for patients and family members or caregivers or both, in aspects of transplantation. |

Source: Explore Transplant Initiative by Waterman et al, 2010

**Transplant Barriers: Dialysis Patient Perspective**

- Patients being overwhelmed coping with dialysis
- Fear and misinformation about transplantation
- Patients not understanding they are potential transplant candidates
- Limited medical training and knowledge of transplant
- Socioeconomic challenges (finances, access to insurance, etc.)
- Racial disparities

Source: Explore Transplant Initiative by Waterman et al, 2010

**Transplant Education: Dialysis Provider Perspective**

- **Advantages:**
  - Multiple opportunities for transplant discussions; often over a number of years
  - Education can occur when patients are most healthy & interested
  - Opportunity to educate all potential candidates

Source: Explore Transplant Initiative by Waterman et al, 2010
Transplant Education: Dialysis Provider Perspective

- **Challenges:**
  - Insufficient provider time
  - Insufficient training in transplant education
  - Lack of access to transplant education materials
  - Potential financial disincentive to refer for transplant

Source: Explore Transplant Initiative by Waterman et al, 2010

Transplant Conditions of Participation

- Mandates transplant programs provide a copy of patient selection criteria to both the patient and the dialysis facility
- Written procedures/policies for ongoing communication with dialysis facility
- Document the transplant program has informed dialysis facility on patient status, including work-up testing required

Transplant Conditions of Participation

- Provide documentation to dialysis facility of ANY decisions made by transplant team – listing, not a candidate, issues to be resolved prior to listing, being placed on hold or being removed from the waiting list.
- ANY decision needs to be in writing to the patient, dialysis facility and referring MD

Psychosocial Barriers to Completing the Transplant Work-up

- Systemic Barriers
- Individual (patient, nephrologist, team members) Barriers

Psychosocial Barriers to Completing Transplant Work-up - Systemic

- Wide differences across different ESRD Network regions in the percentage of patients transplanted
  - Lowest – Region 6 (Southeast)
  - Highest – Region 1 (New England)

Dialysis Center Factors Influencing a Lower Rate of Transplant

- For-profit status
- Patients with a longer time on dialysis
- A higher percentage of African-American patients
- Patients with no health insurance
- Higher percentage of patients with diabetes
ESRD Network 6

- Lowest rates for transplant are in the south and southeast.
- In Network 6, 36 facilities reported NO patients received a kidney transplant over a recent 4-year period of study.

Dialysis Center Factors Influencing a Higher Rate of Transplant

- Greater number of facility staff
- More transplant centers per 10,000 ESRD patients
- Higher percentage of employed patients
- Higher percentage of patients on PD

Factors Influencing Transplant Rates

- 84% of US dialysis facilities are for-profit
- Lower staffing ratios = time constraints on staff, reduced opportunities for patient education

Racial/Ethnic Disparities in Access to Transplant and Rates of Transplant

- Percentage of African-American patients within a facility is associated with a lower transplant rate
- Interplay of race and lower socio-economic status (SES)

Racial/Ethnic Disparities in Access to Transplant and Rates of Transplant

- In the US, racial/ethnic minority status strongly associated with lower SES
- Lower SES is strongly associated with poorer health outcomes, inadequate dialysis and delays in transplant.
- Health outcomes inextricably linked with poverty.
- Those with lower SES receive worse care than those with middle/higher incomes on a majority of all quality care measures

Racial/Ethnic Disparities in Access to Transplant and Rates of Transplant

- Multiple studies over the years demonstrate that ethnic and racial minorities and those with lower SES are less likely to access the multiple steps of the transplant process, or to receive a living or deceased donor kidney transplant.
Disparities in Access to Transplant

The CMS ESRD Network 2013 Statement of Work included a requirement to measure and reduce health disparities in all ESRD network activities including access to kidney transplantation at the dialysis facility level.

Southeastern Kidney Transplant Coalition Study

• About half of the dialysis facilities are not discussing transplant as a treatment option with patients on an annual basis
• Only 19% of dialysis facilities believed that greater than 50% of their patients were interested in transplant.

Southeastern Kidney Transplant Coalition Study

• Only 23% of facilities believed that greater than 50% of their patients were eligible for transplant.
• Estimated that less than 25% of those patients referred for transplant completed the eval process and got listed.

Southeastern Kidney Transplant Coalition Study

• Compared to a study of patients in this region asked about their interest in transplant – 76% of those asked were interesting in receiving a transplant.
• Major misalignment between staff perception and patient interest

Dialysis Facility Education

• No formal transplant education program
• Providers feel unprepared to educate patients
• Most education is brief, not individually tailored to patient’s readiness to pursue transplant, health literacy

Nephrologist-Related Factors

• “Support” prevalent issue for rural nephrologists
• “Evaluation time” more prevalent with urban nephrologists
• Transplant, academic nephrologists and those with >10 years practice more likely to see transplant as the treatment of choice
Individual Barriers to Completing the Transplant Work-up

• Potential bias of both the referring nephrologist and the decisions of the transplant program to consider a particular patient

• The listing process is where human decision is involved to a larger extent; more prone to communication barriers between patients and team and to potential bias and disparities

Individual Barriers to Completing the Transplant Work-up

• Research – link between inadequate patient education and information, poor provider communication or education about kidney transplant and patient difficulty in navigating the pathway to transplant

Individual Barriers to Completing the Transplant Work-up

• Focus Group of Dialysis Patients – 76% stated an interest in receiving a kidney transplant.

• 66% had not been referred for evaluation

Individual Barriers to Completing the Transplant Work-up

Focus Group –

• Lack of information about transplant from dialysis team

• Info that was received not presented in a meaningful manner

• Patients overwhelmed with info or given info in a perfunctory way

• Overall, content of transplant discussions are neither well defined or standardized

Individual Barriers to Completing the Transplant Work-up

Major themes from research studies –

• “Tedious” pre-transplant testing

• Work-up expenses

• Rural patients – distance from the transplant program impedes evaluation

Individual Barriers to Completing the Transplant Work-up

Urban vs. Rural Patients –

• Urban patients more likely to receive transplant info and be encouraged by their nephrologist to pursue transplant

• Rural patients up to 15% less likely to be put on the waiting list for a kidney transplant

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Individual Barriers to Completing the Transplant Work-up

- Patients who reported they had discussed option of transplant with nephrologist were more likely to be put on the transplant waiting list.
- But...nephrologist-reported discussions of transplant did not increase the patient's likelihood of being listed.

Individual Barriers to Completing the Transplant Work-up

- Research shows that in one-third of cases of dialysis providers reporting to CMS that they had discussed transplant with a particular patient, the patient said nobody had discussed transplant with them.

Individual Barriers to Completing the Transplant Work-up

- Major difference between patient and provider reports
- Only the patient reports were associated with the desired behavior

Individual Barriers to Completing the Transplant Work-up

- College graduates were three times as likely to be listed or receive a transplant compared with patients with less than a 12-year education.
- Increased odds of being listed and transplanted with increased educational level.

Individual Barriers to Completing the Transplant Work-up

- Lower educational levels might serve as a communication barrier between patient and health care providers.
- Some evidence to suggest that higher educational levels associated with better adherence.

Individual Barriers to Completing the Transplant Work-up

- Multiple surveys of patients that did not follow through on the transplant work-up process:
- Many patients that are eligible for transplant did not follow through on the complex work-up protocols required to be approved and listed for transplant

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Individual Barriers to Completing the Transplant Work-up

• 83% of the patients said that they did not think they would pass the many medical tests
• A majority were scared of getting a transplant
• A majority didn’t think they could afford the many post-transplant medications

Individual Barriers to Completing the Transplant Work-up

• The majority didn’t remember when or if their MD talked to them about transplant
• Only 7% said their MD talked to them about transplant on more than one occasion
• Many patients believed they had followed up or completed the work-up, when in reality they did not understand the next step in the process that they needed to accomplish

Individual Barriers to Completing the Transplant Work-up

• Most patients said they were uncertain about the process of transplantation, the requirements for listing, their own eligibility, and where they were in the process

Individual Barriers to Completing the Transplant Work-up

The most common barriers to follow-up and listing noted by patients were the result of:
• Misunderstanding
• Misinformation
• Fear

Individual Barriers to Completing the Transplant Work-up

The study authors stated this confusion results from:
• Unclear provider communication
• Misinformation received from peers or other sources
• Misperceptions related to transplant surgery
• Limited health literacy/health decision-making capabilities

Kidney Allocation System

• United Network for Organ Sharing (UNOS) creates policies to regulate the use of donated organs, including how they are distributed to potential recipients
• Under the old system, kidneys matched with recipients largely based on blood type, tissue typing and how long the patient has been on the wait list

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Kidney Allocation System

- Organs not always matched with recipients in terms of the organ's longevity or the patient's expected longevity
- Goal of revised system – do a better job of matching kidneys with recipients – recipients with the longest potential lifespan get matched with kidneys with the longest expected function

Kidney Allocation System

- Kidney Donor Profile Index (KDPI)
  - Scored 0 to 100%
  - Lower the score, the longer the kidney is likely to function compared to other donated kidneys. The higher the score, the shorter timespan that kidney is expected to last.

Kidney Allocation System

KDPI score calculated based on donor factors such as:

- Age
- Height and weight
- Ethnicity
- Stroke as cause of death
- Death due to cardiac death or brain death
- History of hypertension
- History of diabetes
- Exposure to Hepatitis C
- Serum Creatinine

Kidneys with a high KDPI are expected to function for a shorter amount of time compared to other donated kidneys. However, they can still be helpful to candidates that are older and sicker and may not be able to live on dialysis for a very long time while waiting.

Kidney Allocation System

- Transplant Candidates classified with an individual Estimated Post-Transplant Survival (EPTS) score
  - This score also ranges from 0-100% and is associated with how long the candidate will need a functioning kidney transplant compared with other candidates

Kidney Allocation System

- An EPTS score of 20% means that person is likely to need a kidney transplant longer than 80% of other candidates
**Kidney Allocation System**

The EPTS score is calculated based on factors such as:
- Age
- Length of time on dialysis
- Having received a previous transplant of any organ
- Current diagnosis of diabetes

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**Kidney Allocation System**

How are Kidneys Matched?

The 20% of kidneys that are expected to last the longest (those with a KDPI score of 20 or less) will first be offered to patients likely to need a transplant the longest – those patients with an EPTS score of 20% or less.

---

**Kidney Allocation System**

Time on dialysis is still a major factor in when someone gets transplanted.

Under the new system, a candidate’s waiting time starts when they first started dialysis.

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**Kidney Allocation System**

How will this impact your patients?

If your patient has been on dialysis already for a number of years prior to evaluation, the transplant team may slow down the process to make doubly sure the patient is completely ready for transplant before activating on the wait list.

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**Kidney Allocation System**

How might this affect older, sicker patients?

Increased pressure to pursue living kidney donation because a good deceased donor match might be more difficult.

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**Kidney Allocation System**

**Key Interventions**

- Ongoing communication between dialysis and transplant social workers to explain the patient’s EPTS score
- Education on how the new system will affect your patient
- Reality check on what patients need to do
- Help clarify work-up requirements and adherence issues
- Information on living donation
**Collaboration Mandated by CMS**

- CMS Conditions for Coverage (CfC) - Dialysis
- CMS Conditions of Participation (CoP) - Transplant

**Collaborative Interventions to Overcome Barriers**

- Communication
- Education
- Active Advocacy

**Collaborative Interventions to Overcome Barriers**

- Transplant centers need to frequently provide dialysis centers with comprehensive information about eligibility criteria
- Focus on the misalignment between staff perceptions/understanding and patient interest in transplant

**Collaborative Interventions to Overcome Barriers**

- Patient discussion with dialysis staff about kidney transplantation is significantly related to patient access to transplants
- ALL patients without permanent contraindications to transplant should be referred for eval.
- There are very few permanent contraindications; let the transplant center make that determination

**Collaborative Interventions to Overcome Barriers**

- Formally partner between dialysis and transplant to help coordinate education, scheduling work-up testing
- Invite the transplant program to your unit/support group/education day
- Invite transplant social workers to your local CNSW Chapter meeting

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Many patients self-select out for perceived medical contraindications.

Dispelling myths, rumors with accurate information is essential.

In one study, most barriers to work-up and listing were the result of misunderstanding, misinformation and fear.

Education is one of the few modifiable socio-economic factors.

Studies show that racial disparities in access to transplant and transplant outcome may be alleviated in patients with more education.

Assess health literacy – patients can be at very different stages of learning.

Education programs that increase health literacy have been shown to improve the health outcomes of those with lower SES.

What Matters in Transplant Education?

- Early Education through multiple channels
- Unbiased and accurate information
- Tailored education (to learners’ different styles, health literacy, languages)
- Well-prepared educators

Target dialysis facilities with the lowest transplant rates within an ESRD Network.

Target dialysis facilities with a higher proportion of African American patients.

These targeted interventions may be a good opportunity for improving access and reducing variability in the most vulnerable populations.

Important Goal: For an intervention to be effective in reducing racial/ethnic disparities, the interventions must be more effective in the disadvantaged group compared to the advantaged group.

If an intervention improves access and outcomes for all races and ethnicities, it doesn’t reduce disparities at all.
Collaborative Interventions to Overcome Barriers

- Dialysis facility ownership (profit vs. non-profit) is not modifiable
- However, the policies and practices related to transplant within the facility are modifiable
- Is there a conflict of interest that prevents some for-profit units from pursuing kidney transplant for eligible patients?

Collaborative Interventions to Overcome Barriers

Trained Transplant Navigators:
- Met monthly with candidates, providing tailored info and assistance in completing each step in the process
- Control group did not have a navigator
- Those with navigator completed more than twice as many steps as the control group
- Effects of intervention the same across all racial and gender groups

Collaborative Interventions to Overcome Barriers

- Designate a transplant champion/advocate in every unit
- “Everybody needs a cheerleader”

Explore Transplant Initiative

- Created by Amy Waterman, PhD – Social Psychologist at the UCLA Division of Nephrology
- Well-researched: Patients who went through this program were much more knowledgeable about transplant and more likely to begin the transplant process compared to those patients given standard education about transplant
- Quote from Professional using ET: “I knew Explore Transplant would help my dialysis patients, but I didn’t expect it to help me.”
- The focus is on teaching patients about transplant without assuming transplant is the right path to take. “The program is called ‘Explore Transplant,’ not ‘Get a Transplant’”

Explore Transplant Initiative

- Major goal/objective – reduce racial disparities in access to transplant
- Increases knowledge and confidence among providers to discuss transplant with patients.
Transplant Education: Dialysis Perspective

- Transplant education must be tailored by a patient's level of transplant readiness to support informed decision making.

- The Explore Transplant Initiative utilizes Prochaska's Transtheoretical Model of Behavioral Change (TTM) to address gaps in knowledge and maximize thorough transplant decision making.

Source: Explore Transplant Initiative by Waterman et al, 2010

Explore Transplant Initiative

- Using TTM researchers hypothesize that kidney patients are in 1 of 5 stages of readiness:

  **Stage 1 Precontemplation:**
  Not considering or not ready to pursue deceased or living donor transplant.

  **Stage 2 Contemplation:**
  Considering pursuing deceased or living-donor transplant.

  **Stage 3 Preparation:**
  Planning to pursue deceased or living-donor transplant

Source: Explore Transplant Initiative by Waterman et al, 2010

- The ET program recommends assessing patient's level of transplant readiness and then provide factual information and recommendations that are tailored to the patient's stage in transplant decision-making.

Source: Explore Transplant Initiative by Waterman et al, 2010

Explore Transplant Initiative

- Education via the ET program is offered in four meetings with the patient during dialysis

  **Meeting One:** Could getting a transplant add anything to patient's quality of life?

  **Meeting Two:** What would it be like to undergo transplant evaluation and surgery?

Source: Explore Transplant Initiative by Waterman et al, 2010

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Explore Transplant Initiative
Dialysis Patient Education

- **Meeting Three**: What would it be like to involve a living donor?
- **Meeting Four**: What is the right Transplant Action Plan for this patient?

Source: Explore Transplant Initiative by Waterman et al, 2010

Explore Transplant Initiative
Benefits to Dialysis Patients

- Increases patient-informed transplant decision making & transplant pursuit.
- Allows patients to choose the treatment option that's right for them.
- Patients hear a point of view from post-transplant recipients via DVD interviews.

Source: Explore Transplant Initiative by Waterman et al, 2010

Explore Transplant Initiative
Benefits to Dialysis Patients

- Explore the option of living donation by teaching patients about living-donor psychology.
- Teaches skills to approach potential living donors.
- Videos and print materials can be shared with family members and potential living donors to initiate family dialogue.

Source: Explore Transplant Initiative by Waterman et al, 2010

Explore Transplant Initiative
Benefits to Dialysis Staff

- Education designed for use while patients are on dialysis.
- Helps meet CMS guidelines for transplant education.
- Teaches provider to assess a patients' readiness to learn and tailor information appropriately.

Source: Explore Transplant Initiative by Waterman et al, 2010

Explore Transplant Initiative
Benefits to Dialysis Staff

- ET educational videos share transplant recipient and living donor success stories.
- Highly video-based to require less of providers’ time.
- Training available to increase providers’ knowledge and confidence discussing transplant options with patients.

Source: Explore Transplant Initiative by Waterman et al, 2010

Making Transplant Education a Reality in the Dialysis Setting

- Seek more time to conduct transplant education and less on administrative tasks. Focus on the CMS requirements to justify your request!
- Develop multidisciplinary teams to share transplant education responsibilities to reduce burden on individual staff members.
- Plan to start small and educate 1-5 patients who have already expressed interest in transplant.

Source: Explore Transplant Initiative by Waterman et al, 2010

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Collaboration Example

**Dialysis Patient: John**
- Young adult
- African American
- New to dialysis due to uncontrolled HTN
- Complex MH & CD history
- Literacy challenges

**Collaboration Example**

- Dialysis SW used motivational interviewing techniques to assess transplant desire/readiness
  - Patient initially overwhelmed by dialysis
  - Rapport building & quality of life discussions led to transplant education

**Collaboration Example**

- Dialysis SW used motivational interviewing techniques to assess transplant desire/readiness
  - Patient initially overwhelmed by dialysis
  - Rapport building & quality of life discussions led to transplant education

**Collaboration Example**

- Reviewed transplant facility criteria
  - Patient doubtful of candidacy due to MH/CD history & literacy challenges

- Contacted Transplant Social Worker
  - Please don't write patient off
  - Dialysis adherence & observations
  - What does Transplant SW anticipate for TX appointments (i.e. transplant psychiatry/addictions assessment?)

**Collaboration Example**

- Educated patient on what to expect for transplant workup & WHY!

- Patient successfully completed transplant workup
  - Transplant social worker advocated for patient

- Transplant Team Recommendations before listing on deceased donor list:
  - Emotional reaction – angry/frustrated
  - Motivation & follow through
  - Personal Goal Setting & Plan of Care

**Collaboration Example**

- Completed CD treatment requirements & maintains sobriety

- Demonstrates adherence with dialysis treatment plan

- Demonstrates adherence with mental health medications & therapy

- Obtained stable housing with support of AHRMS worker

- Attending GED courses & plans to seek employment

**Collaboration Example**

- Active on Deceased Donor Kidney Transplant List!

- Patient appreciative of Dialysis & Transplant SW support, encouragement, advocacy, coordination of care efforts, etc.

- Dialysis & Transplant Social Workers serving as patient’s cheerleaders!

**Summary**

**Current System:**

- Lack of an organized education system
- Disorganized
- Confusing
- Inadequate

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Summary

• Misunderstanding
• Misinformation
  • Fear

• AND...getting lost along the way

Questions?

Jeff Harder, MSW, LICSW, NSW-C
jharder@uw.edu
206-598-4676

Nicole Baune, MSW, LICSW
baune.nicole@mayo.edu
507-385-6598