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Introduction

- An estimated 1/3 U.S. adults ≥65 y.o. have chronic kidney disease (CKD)¹
- Adults with advanced CKD must make preference-sensitive decisions such as initiating dialysis, which has serious implications on quality of life²⁻⁴
- Clinicians are being called to engage in shared decision-making (SDM) to best support patients⁵⁻⁸
- SDM is a process by which patients, clinicians, & carepartners discuss all options and identify a treatment that best aligns with patient preferences, values, & goals, promoting patient-centered care⁹**
- Few CKD patients report engaging in SDM. Patients do not perceive their care as individualized & don't feel empowered^{10,11}
- Clinicians are unsure how engaged their CKD patients want to be, how to meet informational needs, and how to share the decision-making process¹²

Aim: To understand patient and clinician perceptions of the decision-making process, including patient preferences for engagement and flow of information, and how these preferences impact satisfaction

Methods

July 2018-December 2020

Decision Aid for Renal Therapy recruited patients & clinicians from 4 U.S. regions. Patients were ≥70 years, non-dialysis CKD stage 4 or 5

Quantitative data was collected at baseline, 3-months, 12-months, & 18-months using demographic measures & the Control Preference Scale (CPS).¹³

Qualitative data was collected through 2 waves of semi-structured interviews. Thematic analysis was conducted.¹⁴

January 2023-April 2023

Data from patients who participated in both wave 1 and wave 2 interviews was analyzed using narrative analysis methodology¹⁴ in order to further understand the decision-making experience over time. The CPS data was also analyzed over time independently, and in conjunction with the qualitative data to gain a robust picture of the patient experience.

Control Preferences Scale (CPS)

The CPS is a one item, multiple choice measure with the following answer options, separated into categories:

ACTIVE

I prefer to make the final selection of my treatment after seriously considering my doctor's opinion

I prefer to make the final selection about which treatment I will receive

COLLABORATIVE

I prefer that my doctor and I share responsibility for deciding which treatment is best for me



PASSIVE

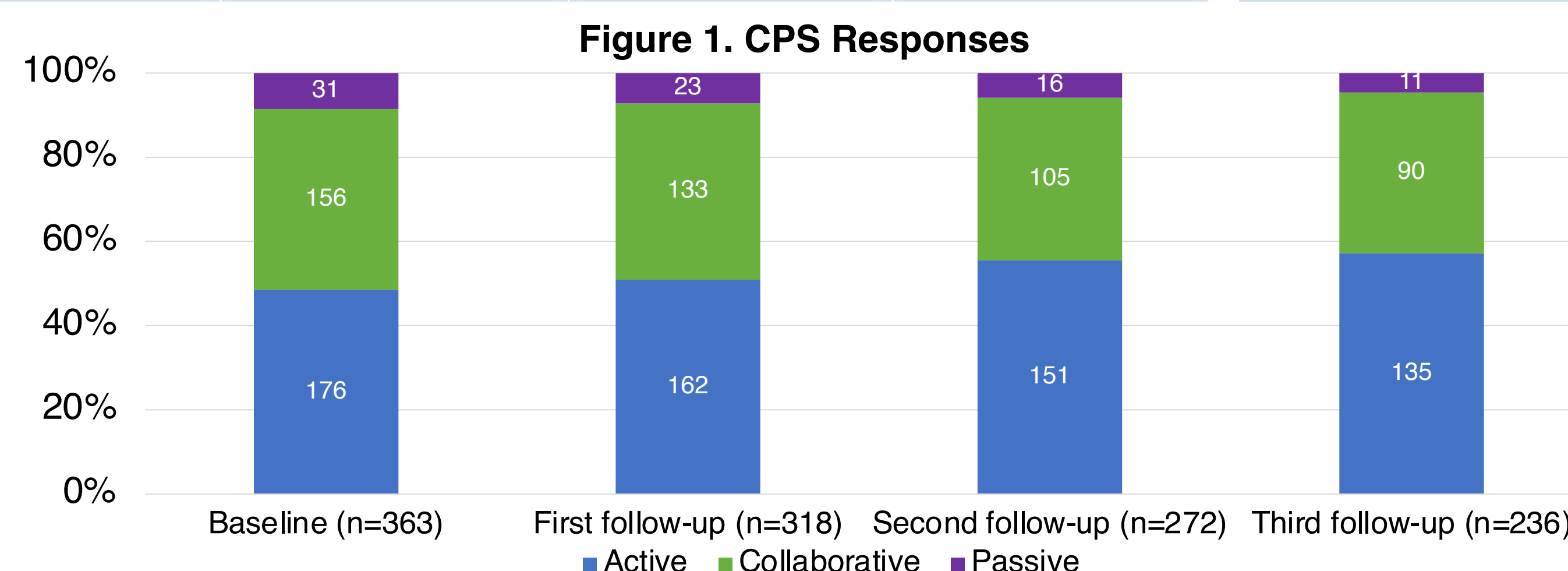
I prefer that my doctor make the final decision about which treatment will be used, but seriously considers my opinion

I prefer to leave all decision regarding treatment to my doctor

Based on graphic from Degner et al.¹³

Results

Patient-participant Characteristics				Clinicians (n=31)
Characteristics	Quantitative (n=363)	Total Qual. (n=44)	Both waves (n=17)	
Female	154 (42.4%)	26 (59.1%)	8 (47.1%)	26 (89.3%) were nephrologists
Black	47 (12.9%)	14 (31.8%)	5 (29.4%)	19 (61.3%) practiced for more than 10 years
Hispanic/Latino	15 (4.1%)	4 (9.1%)	1 (5.9%)	8 (25.8%) from Boston region
High School or less	76 (20.9%)	6 (13.6%)	3 (17.6%)	



Qualitative analysis resulted in four overarching themes:

1A) "I talked to my family members, I talked to our children, I talked to my husband, I talked to the doctors, but ultimately I'm the one who has to live it, I'm the one who makes the decisions" (Patient 16, active preference).

1) Patient preferences for engagement throughout the decision-making process



2) Perceived challenges to controlling the flow of information



2A) "I don't know enough and I feel like I really want to know more" (Patient 20, collaborative preference).

2B) "I felt I'd learned more than a civilian needs to know about the subject" (Patient 28, active preference)

2C) "[I]t's a matter of judging your patients. Some people can hear things at different times. Sometimes what you do is you plant a seed... while there are other people that want to hear everything all at once." (Clinician 8)

3A) "Here's the truth. Doctors don't have time to talk to me about [treatment]. They'll probably send me to some kind of consulting person. They don't lay it out for me... And you just have to accept what the [doctor] says. Because you can't argue with him" (Patient 5, active preference).

3) Impact of misalignment between patients' preference for engagement and actual decision-making experience

4) Increasing satisfaction with SDM experiences



4A) "I made my decision after being in cooperation with the doctor and my husband, the three of us worked it through, and it was pretty simple to decide" (Patient 1, collaborative preference).

4B) "So is it quality of life that they're looking for? Or is it just longevity that they're looking for? So that's usually the springboard for me to then discuss what options they potentially have." (Clinician 13)

Discussion & Conclusion

Our study found that:

- older adults with CKD want to be engaged in the decision-making process, but they don't always play their desired role
- control of information flow is a key element of high-quality SDM
- alignment between control preference and actual decision-making experience can increase patient satisfaction with the SDM process
- One way to facilitate alignment between preference for engagement and actual experience is a strong patient-clinician rapport
- Physicians should regularly ask their patients how engaged they want to be in the decision-making process and what level of control they desire in receiving information
- Power dynamics play a role in patients' abilities to fill their preferred roles

Strengths: Multi-site, included both patients and clinicians, longitudinal, multiple approaches to qualitative data, mixed-methods

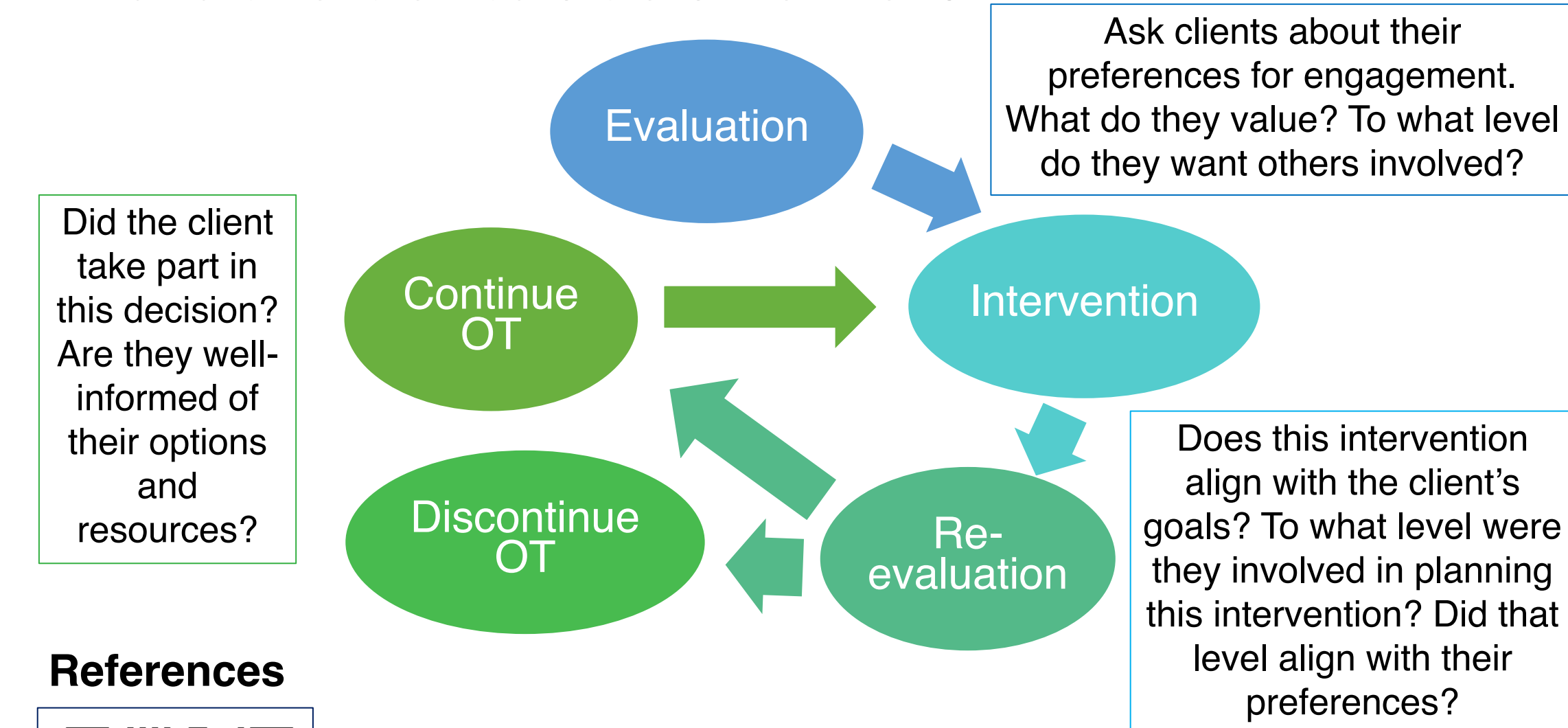
Limitations: Diversity of sample (very few Latinx/Hispanic individuals), not all patients had made a treatment choice by the time of their interview

Future directions

Do preferences for engagement change over time? Do they vary based on cultural or racial background? What structural barriers contribute to misalignment? How can non-nephrologist clinicians better engage in SDM?

OT Implications

- This study focused on older adults who experience chronic illness; a population that many OTs will encounter throughout their careers
- SDM is an evidence-based approach to improving person-centered care in a variety of populations, which can be used by OTs in intervention planning and discharge planning¹⁵⁻²¹
- Another key element to SDM is understanding patients' preferences, values, and goals, which can be integrated into every stage of the OT process (See figure below, adapted from Schell & Gillen²²)
- OTs can ask their clients about their preferences for engagement in order to individualize care & advocate for their clients



References



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