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Patient-Centered Goal Setting in Developmental Therapy: Discordance between Documented Goals and Caregiver-Perceived Goals

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ABSTRACT

Introduction: Productive interactions between engaged patients and clinical teams are key to effective clinical practice. Accordingly, the identification of needs and priorities through the process of collaborative goal setting is fundamental to patient-centered care. Executing a goal-setting process that is truly collaborative is challenging; many caregivers do not feel that they are adequately involved in the goal-setting process. This study presents the results of an initiative intended to understand goal concordance between therapists and caregivers. **Methods:** We conducted an observational, cross-sectional design study. Twenty-nine pediatric physical and occupational therapists developed and documented collaborative goals for their patients. Over 6 months, 120 randomly selected caregivers from a weekly list of patients scheduled for a follow-up physical or occupational therapy visit participated. Caregivers completed structured interviews related to their children's therapy goals. We calculated agreement coefficients between caregiver-perceived goals and therapist-documented goals. **Results:** Overall strength of agreement was poor (M = –0.03, SD = 0.71). There were no significant differences within variables of a goal setter, goal importance, or goal utility. Median agreement coefficients were greatest for goals perceived to be identified solely by the caregiver, perceived as important, and perceived as functionally useful. **Conclusions:** The results of this study underscore the state of discordance in the collaborative goal-setting process in pediatric physical and occupational therapy. Healthcare encounters continue to be framed by provider perspectives and priorities. Developing therapy goals that enhance family involvement, relate to function, and are important to the healthcare consumer may improve the agreement. *(Pediatr Qual Saf 2019;4:e199; doi: 10.1097/pq9.0000000000000199; Published online August 7, 2019.)*

INTRODUCTION

Children and young adults with chronic conditions present with numerous impairments of body structures and functions and activity limitations. Many of these limitations are complex and multifactorial.[1–3] Physical and occupational therapy services are solicited to minimize these deficits and optimize function, which ultimately improves quality of life. By professional best practice,[4] pediatric physical and occupational therapists must focus intervention on activities of value to the family and of interest to the child. This patient-centered approach promotes and empowers the consumer of therapy services.[5,6] One major mechanism for the effectiveness of clinical care is "co-production"—productive interactions between informed, engaged patients and prepared, proactive clinical teams.[7] Accordingly, the identification of needs and priorities through the process of collaborative goal setting is fundamental to patient-centered care.[8,9] Evidence suggests that collaborative goal setting correlates positively to patient satisfaction, adherence to treatment, and healthy behaviors, particularly in the chronic care population.[10] Collaborative goal setting in the rehabilitation setting works to improve caregiver perception of competency and partnership with the therapy team.[11] Therapists and caregivers agree that functional task practice in the home environment is enhanced when goals reflect family preferences.[11] This enhanced practice and activity may ultimately lead to improved performance and outcomes.[5,12] As such, collaborative goal setting and the later achievement

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of co-produced goals may be regarded as critical factors in treatment success.[13]

Despite the well-established benefit of patient-centered goal setting, achieving a truly collaborative process in the clinical setting is challenging.[14,15] More than two decades after the introduction of patient-centered care, healthcare encounters continue to be framed by provider perspectives, which may starkly contrast with patient and family perspectives.[16] Healthcare providers do not understand the "successful conditions of collaborative goal setting" well.[17] Observational studies suggest that therapists struggle to elicit patients' goals, frequently generate therapy goals that do not accurately reflect patient preferences, and ineffectively incorporate patient priorities into goal setting.[9,14,15,18] Although therapists often report that their goal-setting approach was collaborative, families concurrently report insufficient involvement in the process.[18]

Goal concordance between adults with multiple sclerosis and their clinical team members has been investigated.[19] On average, the patients and clinical team agreed on 1.7 of the patient's top 5 goals and disagreed on the most important goal domains, revealing a broad incongruity between patients and their clinical team. Notably, no work has yet examined this phenomenon in pediatric physical and occupational therapy. Efforts to improve collaborative goal-setting practices in the pediatric therapy setting have most recently focused on the construction of therapy goals that reflect valued activity[18,20] or meaningful therapy outcomes.[21] This study presents the results of an initiative intended to understand goal concordance between therapists and caregivers better. Such an understanding may assist in identifying ways to improve collaborative goal setting between patients/caregivers and therapists.

The objectives of this study were as follows: (1) to quantify agreement between therapist-documented goals and caregiver-reported therapy goals; (2) to explore the relationship between goal agreement and perceived goal setter (ie, the individual who generated the goals); (3) to explore the relationship between goal agreement and perceived importance of documented therapy goals; and (4) to describe the relationship between goal agreement and perceived goal utility (eg, achieving this goal will help my child to better…).

METHODS

Participants and Setting

One hundred twenty caregivers of children and young adults receiving developmental physical or occupational therapy at an outpatient academic pediatric medical center in the Midwestern United States participated in this study. Patients (40 females and 80 males) receiving pediatric therapy services ranged in age from 1 to 22 years (M = 5.83 years) with diagnoses of autism spectrum disorder (n = 38), cerebral palsy (n = 14), unspecified lack of coordination (n = 14), Ehlers Danlos Syndrome (n = 6), or another developmental or neurological diagnosis (eg, torticollis, spinal cord injury; n = 48).

Caregivers were randomly selected from a generated weekly list of all scheduled outpatient therapy follow-up appointments and consented to participate in the study. Twenty-nine unique pediatric physical and occupational therapists (average years of experience = 10.0 years) created the goals retrieved for analysis. All study procedures were reviewed and approved by the Institutional Review Board of the medical center.

Study design

Caregiver Report of Goals. Each week, the study team generated a list of all scheduled outpatient visits with a follow-up visit appointment type. From this list, random numbers were assigned to each patient and then ordered. The first 5 patients were selected for participation in the study each week, and weekly data collection continued for 6 months (November 30, 2015 to May 9, 2016; 24 weeks). Caregivers completed waiting room interviews before or after regularly scheduled therapy visits. Efforts were made to protect patient privacy by ensuring that the immediate surrounding area was empty of other patients or interviews occurred in private treatment rooms. To minimize bias, an independent assessor, with no active role in study design, conducted the interviews. There was only one assessor involved in the study. The assessor was a research employee of the medical center with no involvement in the creation of the goals (ie, the assessor was not a therapist) and received approximately 2 hours of training from the study team before conducting the interviews. If the assessor was unavailable for a selected visit, a phone interview occurred instead. The assessor interviewed each caregiver once, and no caregivers declined. All interviews were scripted and structured, and caregivers were not contacted for further follow-up. The assessor asked caregivers the following questions:

1. Do you know what your child's current (short-term and long-term) therapy goals are? If so, can you tell me about them? [Assessor recorded caregiver-reported goals.]
2. Your child's therapist, [Therapist Name], also has written down some goals. [Assessor read goals extracted from the electronic medical record aloud.] Do the goals that he/she wrote down feel important to you today? Your choices are: "not very much," "some of them do, and some of them don't," or "yes they are all important."
3. If [Patient Name] achieves the goals that your therapist has written down, do you think that he/she will be able to do more everyday activities or be more involved in everyday life situations? Your choices are: "no, I don't think so," "I'm not really sure," or "yes definitely."
4. Do you remember who helped to create the goals that your therapist has written down? Your choices are: "I did," "someone else in my family did," "the therapist did," "we did it together (therapist and family)," or "I can't remember."

Therapist Report of Goals. Goal setting is a routine part of the therapy treatment and documentation process. At the institution of the current study, outpatient therapy follow-up notes typically contain 1–5 current therapy goals, the status of the goal, and progress toward the achievement of each goal. Goals are encouraged to be established collaboratively between the patient/caregiver and therapist (eg, collaborative goal setting is reinforced in departmental meetings). We extracted therapy goals for the selected patients from the medical record for analysis on the day of interviews. Short-term and long-term goals were selected from the patient's most recent therapy note. In physical and occupational therapy, goals are established at the initial evaluation and updated every progress note. The treating therapists were blinded and not made aware of the current study until we shared nonidentifiable results at a later staff meeting.

Data Analysis

The primary intent of this quality improvement work was to quantify concordance between therapists and caregivers on perceived or reported therapy goals. Gwet's agreement coefficient[22,23] was employed to quantify concordance. We selected Gwet's AC_1 in the present study as the statistic has the flexibility to account for categorical and/or missing data. The measure overcomes the "kappa paradox" (ie, marginal totals can dramatically lower a high value of agreement, and substantial differences between raters can increase kappa estimates). Even an adjusted kappa is not able to account for this.[23] Gwet's AC_1 has been determined to be a more stable measure of agreement compared to Cohen's kappa[23]; it has been associated with favorable psychometric properties[24] and includes a correction for chance agreement. An intraclass correlation was not selected, as this statistic is more commonly used with multiple coders and ordinal or ratio data.[25]

An independent assessor completed a preliminary data reduction process by determining the number of goals identified by the caregiver during the interview that matched or were in close agreement with the goals documented in the medical record by the therapist. A decision to "agree" was based on goal content. For example, if a therapist documented that the patient is working to maintain feet on pedals for 20 feet during nonadapted bicycle riding, and a caregiver reported that the focus was on independent bike riding, this would be counted as an agreed upon goal. If one party mentioned a goal, but not the other, the assessor recorded a disagreement. We counted the total number of agreed upon and disagreed upon goals for each child and aggregated data weekly. The study team trained the assessor in the "agree" criteria before study commencement.

An interpretation of the strength of agreement between caregiver-reported therapy goals and documented therapist goals was determined using Gwet's AC_1 cutoff scores as follows: <0.20 = poor; 0.21–0.40 = fair; 0-41-0.60 = moderate; 0-61-0.80 = substantial; and 0-81-1.00 = almost perfect.[23,26,27] In terms of the present study, 1 = the most agreement possible (eg, caregiver identified all documented goals and all caregiver-reported goals were documented), and –1 = the most disagreement possible (eg, caregiver did not identify any documented goals and no caregiver-reported goals were documented).

We completed descriptive and inferential statistics in R (Version 3.5.1) and RStudio (RStudio, Inc., Boston, Mass.). As the assessor asked caregivers interview questions regarding goal setter, goal importance, and goal utility, we also analyzed agreement data by subgroup. Because not all groups were normally distributed, the study team calculated a Kruskal–Wallis statistic.

RESULTS

The overall mean Gwet's AC_1 value was –0.03 (SD = 0.71, range = –1.00 to 1.00). Sixty-five percent (79 of 120) of the therapist-caregiver pairs revealed poor agreement (ie, $AC_1 < 0.20$), 11.7% (14 of 120) demonstrated moderate agreement (ie, $AC_1 = 0.41–0.60$), and 18.3% (22 of 120) demonstrated perfect agreement (ie, $AC_1 = 1.00$). Less than one percent of the pairs showed fair ($AC_1 = 0.21–0.40$; 1 of 120) or substantial ($AC_1 = 0.61–0.80$; 4 of 120) agreement. Of the 22 therapist–caregiver pairs reflecting perfect goal agreement, 90.9% of caregivers perceived collaborative establishment of goals, 100.0% of caregivers reported that the goals were important, and 90.9% of caregivers perceived that the goals were functionally useful.

We calculated a Kruskal–Wallis statistic for each variable (ie, goal setter, goal importance, goal utility). There was no significant difference in the median AC_1 among the 5 levels of a perceived goal setter, $H(4) = 7.37$, $P = 0.12$. Likewise, there was no significant difference in the median AC_1 among the 3 levels of perceived goal importance, $H(2) = 3.07$, $P = 0.22$, nor was there a significant difference in the median AC_1 among the 3 levels of perceived goal utility, $H(2) = 2.24$, $P = 0.33$.

Median agreement coefficients were greatest for goals perceived to be identified solely by the caregiver (Fig. 1), perceived as important (Fig. 2), and perceived as functionally useful (Fig. 3). See tables 1–3 (Supplemental digital content 1–3, which display descriptive statistics of Gwet's agreement coefficient as a function of a goal setter, goal importance, and goal utility, http://links.lww.com/PQ9/A121, http://links.lww.com/PQ9/A122, and http://links.lww.com/PQ9/A123) for a complete summary of descriptive statistics.

DISCUSSION

This study presented the results of an initiative seeking to quantify concordance between caregiver perception of developmental physical and occupational therapy goals and goals documented in a patient's medical record by

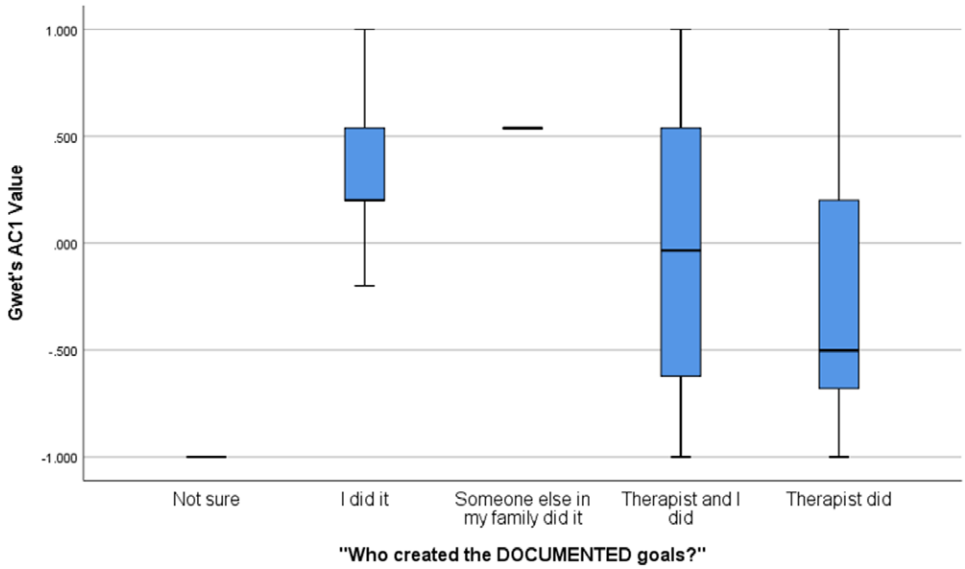

Fig. 1. Boxplots of Gwet's agreement coefficient (AC_1) as a function of a goal setter. Median AC_1 was greatest for caregivers who perceived that they established the goals, followed by the therapist and caregiver together, and the therapist alone, respectively. The absence of tails in the "Not sure" and "Someone else in my family did it" conditions is reflective of only one caregiver giving this response in each condition.

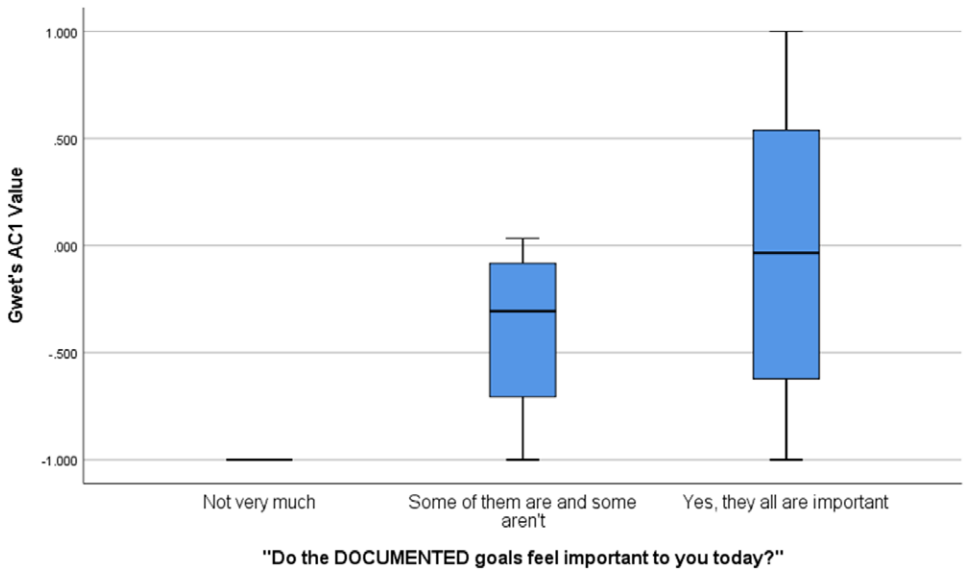

Fig. 2. Boxplots of Gwet's agreement coefficient (AC_1) as a function of goal importance. Median AC_1 was greatest for caregivers who perceived the documented goals as important, followed by caregivers who perceived some of the goals as important. Only one caregiver perceived that the documented goals were not important.

the treating physical or occupational therapist. Results revealed a broad discordance between caregiver-perceived therapy goals and therapist-documented goals.

Discordance between caregiver-perceived therapy goals and therapist-documented therapy goals has important implications for therapy care plans, therapy progress, and therapy outcomes. The results of this study support the proposal that a reliable process for achieving collaborative goal setting in chronic care through conversation, understanding patient values, and setting shared goals (with mutual responsibility and accountability)[16] does not yet exist at this specific site. Moreover, when concordance between caregiver-perceived goals and therapist-documented goals is poor, as observed in the present study, opportunities for reinforcement at home or in the community may be diminished, and therapy doses are likely to be inadequate.[28] Motor skills are likely to be underpracticed, learning is less likely to progress beyond the therapy setting, and goals are less likely to be achieved.

Current evidence supports the notion that caregivers should take ownership of goals and act as a "driver" in the goal-setting process.[11] Concomitantly, caregivers

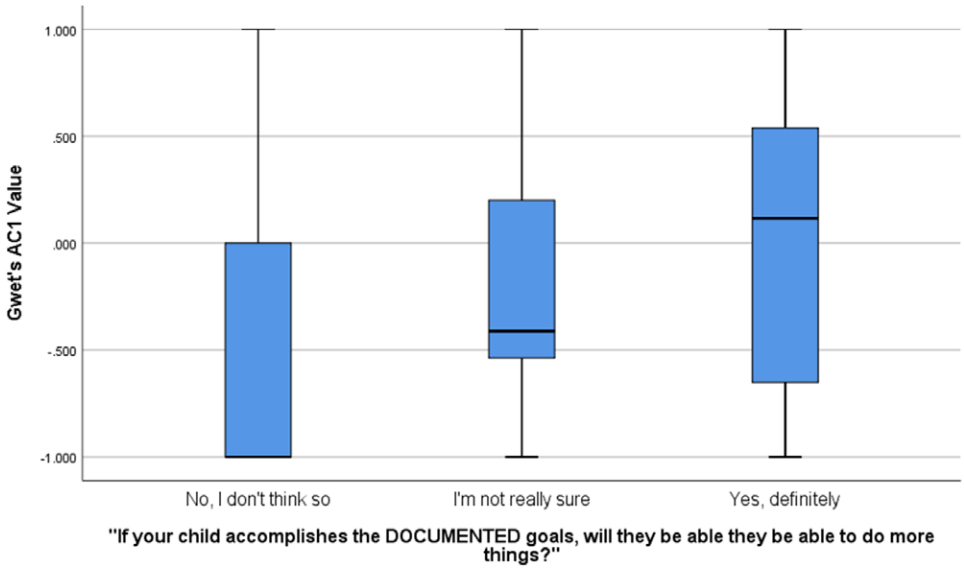

Fig. 3. Boxplots of Gwet's agreement coefficient (AC_1) as a function of goal utility. Median AC_1 was greatest for caregivers who reported the functional utility of the documented goals, followed by caregivers who were not sure about the functional utility, and those who did not perceive the goals as functionally useful.

consistently report that they experience enhanced feelings of competence when creating goals collaboratively with a professional. Caregiver perception of competence declines if given too much responsibility.[11] Indisputably, collaborative approaches to goal setting are favored in pediatric rehabilitation.[14,15,18,29] However, as this study illustrates, improved efforts are required to ensure mutual responsibility and accountability following a goal-setting methodology that is regarded by both parties as "collaborative."

Despite an overall summary of poor agreement, it is important to note that over 95% of caregivers felt that the documented goals were important, and 83% of caregivers felt that the documented goals were useful to their child's performance of functional activities. This finding is encouraging for caregivers who are hesitant to determine goals for their children independently. Caregivers consistently report that they respect the professional competence and supervision provided by therapists in the goal-setting process.[11] Moreover, some caregivers do not feel comfortable identifying goals for their children at a young age, secondary to unfamiliarity with the condition and available therapeutic interventions.[18] In these cases, parents prefer to yield to the expertise of the therapist to determine realistic, meaningful goals.[18] The results of the current study suggest that therapists remain successful at creating meaningful goals, despite discordance.

To improve goal agreement between caregivers and therapists, we recommend that goals be established with enhanced family involvement, focused on functional content, and identified as a current priority to the patient and family. These characteristics were present in the majority of goals reflecting near perfect agreement. In a study examining goal agreement between adult patients with diabetes and their physicians, agreement improved with increased education and discussion of treatment goals.[30] As illustrated in Figure 4, the study team developed a key driver diagram with proposed interventions, including the development of a goal-setting tool that employs meaningful areas of the International Classification of Function, Disability and Health.[31] We further propose that standard processes for goal setting be studied carefully to ensure fidelity and that therapists subsequently review identified goals with caregivers at regular intervals. Caregiver learning strategies could be investigated to determine the most appropriate method (eg, written and visual) for clearly communicating goals. The health literacy of the caregiver might also be considered, as a greater percentage of individuals scoring in the lowest levels of literacy proficiency are expected in the next 10 years.[29,32] Caregivers generally favor goals that are concrete, observational, written, and visible to everyone involved with the care of the child.[11] It is important to recognize that caregivers of children with developmental disabilities experience increased life demands and struggle with balancing therapy in the context of everyday life.[18] By providing caregivers with optimal education materials to understand and implement goals in the home and community settings, we hope to ameliorate this burden and improve outcomes.

Although the case for the integration of personal goals is compelling, a paucity of effective strategies for seamless clinical workflow integration[33] means that clinicians often lack skills to: (1) elicit patient goals, preferences, and values and (2) tune care to align with these aims.[34] Without a reliable process for shared goal setting, outcomes will remain suboptimal. Incorporating a patient and caregiver's perspective into the goal-setting process requires education and skill.[15] Therefore, we recommend that therapists complete training in a standardized

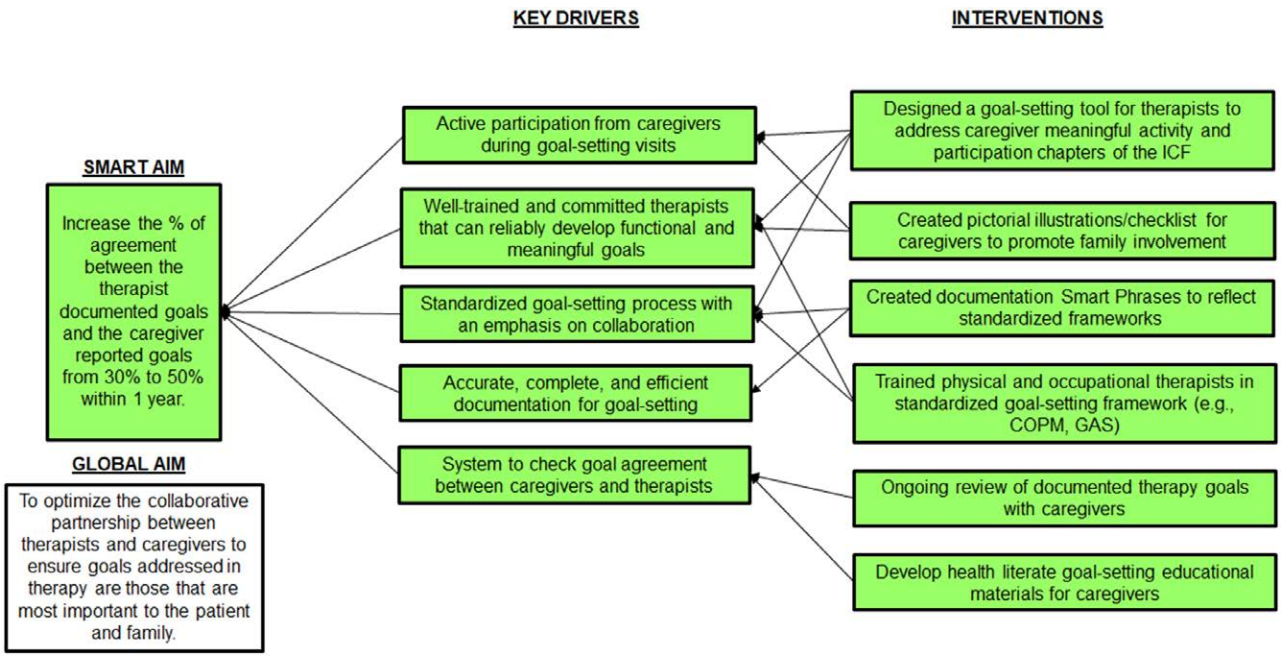

Fig. 4. Key driver diagram for improved goal concordance between therapists and caregivers. Key drivers reflect caregiver and therapist factors. The study team developed the proposed interventions. COPM, Canadian Occupational Performance Measure; GAS, Goal Attainment Scaling; ICF, International Classification of Function, Disability and Health.

goal-setting procedure (eg, Goal Attainment Scaling). Some sources recommend that therapists train up to 8 months before implementing a standardized goal-setting procedure.[35] A clinical environment that supports family-centered care should recognize the benefits of collaborative goal setting and provide therapists with the time and support necessary to receive proper training in a collaborative goal-setting procedure.[14]

LIMITATIONS

Although every effort was made to minimize bias, the determination of the number of goals in agreement versus disagreement was subjective. The use of a single rater precluded our ability to determine the interrater reliability of goal coding. Future work in this area should address this limitation through the implementation of multiple assessors to obtain a measure of interrater or intrarater reliability. The goals established for each child were not necessarily independent of each other. Thus, limited caregiver understanding of one goal may have influenced the understanding of a related goal. As the purpose of this study was to determine overall goal concordance, we did not analyze the data by the number of years in therapy.

Additionally, we did not account for the influence of covariates such as age, type of therapy, or diagnosis. Analysis concerning these variables is an important direction for future work in this area. This study did not account for recall bias. It is possible that poor agreement occurred as a result of caregivers simply not being able to recall their child's therapy goals. However, it is notable that only 7 of the 120 caregivers (<6% of caregivers) were unable to recall any goals. In striving toward mutual responsibility and accountability in goal setting, it is crucial that all parties are aware of the child's therapy goals. Finally, we selected caregivers randomly from a list of patients receiving therapy services at a Midwest academic medical center. Although this population is ethnically and culturally diverse, our findings may not be entirely generalized to children outside of this specific medical center or other therapies.

CONCLUSIONS

The results of this study underscore the state of discordance in collaborative goal setting in pediatric physical and occupational therapy. Despite the construction of therapy goals in a context viewed as collaborative, the strength of agreement was poor. These findings substantiate claims that healthcare encounters continue to be framed by provider perspectives and priorities. Developing therapy goals that are established together, related to function, and important to the child and family may improve the agreement. Caregiver and therapist education regarding goal setting may also improve concordance.

DISCLOSURE

The authors have no financial interest to declare in relation to the content of this article.

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