Forward anchoring in transformative agency: how parents of children with complex feeding difficulties transcend the status quo

Abstract

To understand how people change the course of their own lives and the lives of those around them, we need to understand the dynamics of agency. Sannino's (2015) model of transformative agency by double stimulation (TADS), centres on how people use auxiliary tools to break away from conflicts of motives. Focusing on the serious but overlooked problem of feeding-tube dependency in childhood, the paper asks: How do parents enable their child to feed orally when the 'given' future remains dependent on a feeding tube? Analysis of two successful but different processes deploys Sannino's metaphor of forward-anchoring – pulling on stable anchors to move towards unknown solutions. As primary caregivers, two mothers broke away from conflicts of motives by searching, regaining control and then pulling forward on through diverse arrays of actions. The paper contributes new insights in an area where agency is vital yet hardly studied. It reveals how what is often regarded as a biomedical or clinical problem can be understood in radically different, future-oriented terms that recognise parents' agentic contributions, and the everyday means that can be crucial in breaking away from underlying conflicts of motives.

Keywords

Agency; double stimulation; cultural-historical activity theory; feeding difficulties; parenting; tube weaning

1. Introduction

To understand how people change the course of their own lives and the lives of those around them, we need to understand the dynamics of agency. How do people transcend the status quo, breach social orders, and take concrete steps towards futures other than those that appear to be 'given' (Gutiérrez et al., 2019; Stetsenko, 2020a)? Cultural-historical scholars have taken up this position in studies of how people enact utopias (Sannino, 2020a), usurp systemic racism (Bal et al., 2021; Ko et al., 2021), and fight back against educational inequalities (Cunha Jr et al., 2019). This paper focuses on the significant but often overlooked problem of feeding-tube dependency in childhood. Feeding tubes are used when children are unable to eat orally. Often the intention is for this to be a temporary arrangement. However, it is increasingly recognised that the tube can shift from being a solution to becoming a problematic barrier to the child feeding orally. The following research question is addressed: How do parents enable their child to feed orally when the 'given' future remains dependent on a feeding tube? The transition to oral feeding, known as tube-weaning, has traditionally been framed as a biomedical or clinical problem. However, these framings focus on the present rather than the future, and overlook parents' crucial role in such significant transformations for the child and family.

This paper focuses on two cases where the tube-feeding status quo was overcome: one overcoming inertia and reluctance in the healthcare system; the other creating conditions so that the family was comfortable to remove the tube. Sannino's (2015) model of Transformative Agency by Double Stimulation (TADS) is used to identify and explain these processes. The analysis reveals that despite apparent differences, the underlying dynamics of change had in common the use of forward-anchoring as a means to escape conflicts of motives that arose in the transition from tube to oral feeding. This casts new light on how tube-free futures can be secured, recognising parents' agentic contributions, contingent as they are on auxiliary means and contributions of others. The analysis enables a critical reflection on the metaphor of forward-anchoring within TADS, finding that the metaphor strains in places against the empirical complexities revealed, but overall remains valuable as a means to empirically capture the dynamics of agency in the wilds of everyday life.

2. Transformative agency by double stimulation

Agency involves the production of possible futures (Gutiérrez et al., 2019). It is a matter of productive, material action, *and* envisioned futures, hopes, dreams, and imaginings of alternative worlds (Rainio & Hilppö, 2016; Sannino et al., 2021; Stetsenko 2020a). Agency involves motives, interacting with and shaping ones world and that of others through mediational means, (Edwards, 2020; del Río & Álvarez, 2007). A recent surge of interest in agency has reinvigorated theorisations of what can be a problematic concept (Stetsenko, 2019). The difficulty with agency is to avoid binary opposition between individuals and social structures, to acknowledge individual contributions without shrinking from communal or social features (Nardi, 2017; Stetsenko, 2020a).

Cultural-historical theories retain a pivotal role for human agency while avoiding dualistic traps, (Cole et al., 2019; Sannino & Engeström, 2018). Grounded in dialectical relations, and recognising the consequences of human action, these approaches explore 'the adaptive and innovative opportunities that humans create through agentic projects with each other and the natural world, rather than as against each other and the world' (Cole et al., 2019, p. 283). Agency is not a property of individuals but emerges in materially mediated social interaction, enabled and constrained by societal and material structures (Roth et al., 2009). Human agency 'can be duly restored without falling into the traps of traditional individualism and anthropocentrism' (Stetsenko, 2020b p. 66). Accounting for the material world that human actions rely upon and aim to transform extends agency 'beyond the skin of the individual' (Sannino, 2015a, p. 1).

2.1 Double stimulation as a principle of transformative agency

Transformative agency by double stimulation (TADS) emerged from and extends what Engeström and Sannino (2020) describe as four generations of cultural-historical activity theory or CHAT. TADS addresses the emancipatory possibility of actions (the first generation of CHAT), how people collectively secure what Leont'ev (1978) referred to as a different fate (second generation), and the negotiations and deviations as people with different expertise work together in fluid collaborations (third generation). Engeström and Sannino (2020) link TADS with 'fourth generation' interest in enacted utopias through heterogenous work coalitions. TADS extends Vygotsky's (1997) work on self-control, seeking to realise the radical potential of double stimulation (Engeström, 2007), bringing together notions of motive, intentionality, volitional action, and agency. Grounding agency in material action, it rejects concepts of agency as a 'sense' that people have, or an individual capability (Sannino, 2020a). TADS refers to a process in which people 'intentionally break out of paralyzing circumstances by transforming them with the help of artifacts they develop and put into use' (Sannino et al., 2021, p. 4), in so doing changing the circumstances of their actions, and themselves.

TADS understands transformative agency as clusters of volitional actions that break away from established, constraining frames, taking initiative to transform the situation (Sannino 2015b; Sannino et al., 2016). This combines a focus on concrete actions with the search for new possibilities, which may begin with individual initiatives, but typically require collaborations to be sustained and expanded beyond particular moments (Haapasaari et al., 2014). TADS elevates double stimulation from an epistemological principle of formative intervention to a principle and concrete basis for transformative agency (Sannino, 2015a, 2015b). The TADS model was developed and tested in an experimental setting, based on Lewin's classic waiting experiment (Sannino & Laitinen, 2015), which was discussed by Vygotsky (1997) in relation to volitional action.

The starting point of the model is a problematic situation which triggers a paralysing conflict of motives – the first stimulus. In the waiting experiment, the conflict is between the staying as asked by the researcher, and leaving, given one has been left waiting with no purpose (Sannino & Laitinen, 2015; Sannino et al., 2016). In efforts to end homelessness, conflicts arose for staff in a housing unit between a traditional guard-like way of

working, and a new approach that promoted casual interactions with residents, but left some staff in fear of residents (Sannino, 2020a). Conflicts also arose for homeless clients between living a healthy life in newly available apartments versus continuing to abuse drugs and alcohol (Sannino, 2018). In everyday parenting practices, documented conflicts of motives include when a child refuses food and becomes distressed during feeding: the parent wants the child to eat, but does not want to upset the child (Hopwood & Gottschalk 2017, 2022).

TADS suggests that people turn to artefacts as mediational means (second stimuli) and imbue them with special meaning as auxiliary motives (Engeström et al., 2020; Sannino 2015b, 2018, 2020a; Sannino & Engeström, 2018). The use of the second stimulus reframes a problem and provides a pathway to resolve the conflict: instead of being at the mercy of the opposing motives, the person takes control of their behaviour. In the waiting experiment, participants used a clock to help make the decision when to leave (e.g., I will leave when it reaches half past the hour).

Outside of experimental settings, these processes are messy, temporally dispersed, and iterative, especially in contexts where the problematic situation reoccurs, re-activating the conflict of motives (Hopwood & Gottschalk, 2017, 2022). The repeated implementation of second stimuli strengthens the person's capacity to take further actions, and has been referred to as 'sticking to the second stimulus' (Engeström & Sannino, 2020, p. 169). Staff in the housing unit used the coffee cup repeatedly in initiating casual interactions with residents, developing transformative agency 'to the point that the staff member discovers new capabilities he had ignored before and qualities in the resident that he had equally ignored' (Sannino, 2020a, p. 170). Transformative agency can emerge when parents put auxiliary artefacts to use in ways that promote new understandings and new possibilities for action in caring for their children. Over time this can transcend specific situations and ultimately change the conditions in which parenting practices unfold (Hopwood & Gottschalk, 2022). Key to this is a more recent addition to TADS, the notion of forward anchoring.

2.3 Forward anchoring

Sannino uses the metaphor of kedge anchors to further explore the function of second stimuli in agency formation. Unlike anchors used to stop vessels from moving, kedge anchors enable people to move when it a vessel is stuck: once the kedge anchor settles on the ground, it is pulled on – a process called warping (Sannino, 2020b). The alternative term 'forward anchoring' emphasises stepping into the unknown and contrasts 'anchoring backward', where background knowledge and stable representations are used to explain a problem and act.

> Second stimuli understood as forward-oriented kedge anchors are instrumental in the elaboration of new meaning which may be stabilised to the point of supporting transformative actions in problem situations for which there are no known solutions. (Sannino, 2020b, p. 4)

Sannino (2020b) enriches the metaphor with reference to different kinds of actions: *throwing* actions, searching for suitable ground; *taking-over* actions: once the kedge is hooked, the crew regains control of the situation; the vessel is still in troubled waters, but the crew now have the means to manoeuvre it; and *breaking-out* actions: the kedge is pulled on, and the vessel is moved away from the problem area.

Forward anchoring involves stepping into the unknown, rooted in commitments to an envisioned future (Sannino et al., 2021). Kedge anchors can take various forms. Sannino (2018, 2020a, 2020b) identified diverse anchors in work on homelessness: joint cleaning activities enabling productive discussions between a counsellor and resident; agreements with shopkeepers to have alcohol and food costs put on a resident's account; agreements not to receive visits overnight (associated with the sale of drugs); bowls of oatmeal with coffee, that helped staff 'stick' to new ways of working that were less guard-like and more interactive with residents; and a

'history wall' erected in a supported youth housing unit, which represented collective memory and exposed contradictions associated with new strict rules that restricted interactions with clients due to safety concerns.

In Hopwood and Gottschalk's (2022) study of TADS in parenting education, kedge anchors were different again. Repeatedly these involved ideas that were directly linked to embodied actions. One mother felt conflicted when feeding her daughter: not wanting to upset the child who was refusing food, but also wanting to ensure she ate. An auxiliary motive was established in such situations to *be with* the child in a calm way. The kedge anchor was the idea of time-out to focus on herself and alleviate her stress, pulled on the anchor with actions of slow breathing. Over time this transformed family mealtimes into a joyful way of being together. The same anchor and actions helped respond to the child's distress when she was teething. For another mother, a kedge involved the idea of self-care, with pulling actions of a nap or yoga transforming the time they had together when awake (Hopwood & Gottschalk, 2022, p. 47).

This paper draws on TADS to understand the dynamics of agency in relation to a significant problem, when children become unnecessarily dependent on a feeding tube. Accomplishing a transition to oral feeding has not been considered previously in terms of agency, but, as the analysis will reveal, such a perspective reveals many crucial aspects of the struggles experiences and how they can be overcome. This extends the application of forward-anchoring in the 'wilds' of everyday life (Engeström & Sannino, 2012; Engeström, 2020) outside previously documented settings of researcher intervention.

3. Tube-feeding in childhood

This section outlines tube-feeding, explains how it can become a problem rather than a solution, critiquing biomedical and clinical framings of tube-feeding dependency.

3.1 Reasons for and prevalence of tube-feeding

Feeding difficulties can have wide-ranging and serious consequences for the health and wellbeing of the child and their family (Hopwood et al., 2020; Hopwood, Moraby et al., 2021). They arise in 20-50% of children, and for 3-10% are severe or persistent, constituting a paediatric feeding disorder (Goday et al., 2019; Pedersen, 2021). Where children are not able to feed orally, feeding tubes safely deliver nutrition to the digestive system, maintaining growth, and preserving life. A tube that passes through the nose (nasogastric or NG) is often used initially. When tube-feeding extends beyond several weeks, a percutaneous endoscopic gastrostomy (PEG) or other surgically emplaced tube is recommended, because these are less prone to dislodgement.

The need for tube-feeding is linked to premature birth, congenital heart disease, cerebral palsy, cystic fibrosis, neurodevelopmental disabilities, metabolic disease, cleft palate, and when children are critically unwell or recovering from surgery (Yi, 2018). Estimates suggest between one and 92 per 100,000 children tube-feed at some point, with real figures believed to be much higher (Krom et al., 2019). Feeding tubes solve the problem of nutrition but are associated with several untoward effects, including increased vomiting, loss of appetite, and active food refusal (Dunitz-Scheer et al., 2009; Pahsini et al., 2016). Carers may experience elevated anxiety, distress and social isolation (Hopwood et al., 2020; Hopwood, Elliot et al., 2021; Wilken, 2012).

3.2 When the solution becomes the problem: tube-feeding dependency

Tube-feeding dependency refers to situations where a child *could* feed orally but continued use of a tube inhibits their learning and ability to do so (Tilyard et al., 2020; Wilken et al., 2018). Rates of such dependency have increased (Wilken et al., 2018), and 'the medical, psychological and economic costs of tube dependency in

pediatric patients are well established' (Tilyard et al., 2020, p. 320). Feeding tubes can shift from being the solution to becoming an unnecessary problem (Dunitz-Scheer et al., 2009).

Stopping tube-feeding is often more difficult than starting it (Forbes & Grover, 2015). Existing research tends to frame this either as a biomedical or a clinical problem. Focusing on nutrition and weight gain can blind clinicians to wider problems, and the security of tube-feeding can lead to deferral of weaning, the success of which is often uncertain (Lively et al., 2019). A biomedical gaze focuses on deficits in children, such as oral-motor, sensory, and developmental feeding problems and behaviours that make weaning difficult (Wilken et al., 2018). Feeding requires coordinated interaction of several bodily systems, which typically develops in the context of a caregiver-child dyad over time as children are offered different textures of food (Goday et al., 2019). This coordination is disrupted and such learning is not available to many children who tube-feed, meaning offering solid food can pose risks. Food in the mouth may be unpleasant for children who have little or no experience of it, and some children may have oral aversion.

There are problems with this framing. One of these is that the deficits in children regarded as barriers to oral feeding may be presumed but not actual (as the case of Jessica, discussed below, illustrates). Avoiding oral feeding because of what a child is assumed not to be able to do can prevent the child from learning the skills that oral feeding requires, perpetuating tube-feeding. Another problem is that this view focuses on what a child is presently deemed unable to do, rather than on how the future might be different. Focusing on the child's bodily functions neglects the many social influences on feeding, particularly those of a child's primary caregivers. Parenting practices have incredibly strong and long-lasting effects on feeding (Daniels, 2019). Thus, biomedical can problematically overlook parents, for whom the consequences of ongoing tube-feeding are keenly felt, and without whose involvement, tube-weaning will not be possible.

Feeding-tube dependency has also been framed as a clinical problem. Few Australian hospitals offer tube-weaning programs as also noted of the UK (Gardiner et al., 2014). Knowledge of successful tube-weaning processes is limited, with a lack of clear clinical guidance leaving practitioners often unsure of when and how to wean (Dovey et al., 2018; Syrmis et al., 2020). This results in a common lack of tube-exit strategy when tube-feeding is initiated (Edwards et al., 2016; Syrmis et al., 2020; Tilyard et al., 2020). While clinicians therefore tend to focus on how tube-feeding solves the nutritional problems of the present, this can overlook the future orientation that matters to many parents who are eager to transition to oral feeding, but report gaps in information provided by clinicians around oral aversion and preventing feeding-tube dependency (Syrmis et al., 2019). Research documents frustration among parents who had no sense of how and when tube-weaning might be possible (see Dadich et al., 2021; Hopwood et al., 2020). This situation marginalises parents and compromises their potential contribution as agents in the transition towards oral feeding (Hopwood, Elliot et al., 2021).

Parents may be wary of the risks to their child if tube-weaning fails. A conflict of motives arises because a tube-free future involves ceasing to use the very device that keeps the child alive. Neither the biomedical nor clinical framings of feeding-tube dependency adequately recognise this conflict, nor provide the means to understand how to break away from it. This is where TADS comes in, offering a distinctive alternative.

4. Data collection and analysis

This paper analyses two contrasting but successful cases of tube-weaning. These are drawn from a study in which interviews were conducted with 41 parents with children who were tube-fed, of whom six had children who transitioned to oral feeding. A further six interviews were conducted, lasting between 45 and 60 minutes, in which these parents were asked to tell the story of tube-weaning.

The first analytical step focused on conflicts of motives, identifying data pertaining to the core conflict (wanting to remove the tube vs wanting to keep it in for safe nutrition), and more specific conflicts that arose. The next

step was to identify auxiliary motives that emerged, breaking away from the entrapping conflict. These were not expressed directly as such, but as interim purposes or steps that became foci for parents' attention.

Then, the analysis focused on second stimuli, designated as kedge anchors used in forward-anchoring if they met two criteria. They had to be a means that helped parents become *unstuck* (upholding the metaphor of use for movement rather than stasis). Second stimuli were analysed as kedge anchors if they involved the elaboration of *new* meaning through 'personal sense-making, social interaction and experimentation embedded in the materiality as a problem' (Sannino, 2020b, p. 4). Such meanings had to support new actions that whose effects could be linked analytically to the transformation from tube-feeding to oral feeding. This distinguished forward-anchoring from anchoring backward (Sannino, 2020b)

Next, the analysis focused on the actions used to pull on these kedges, following Sannino (2020b) in discerning throwing/searching, taking-over/regaining control, and breaking-out/moving away actions. New new accounts of the six transformations from tube- to oral feeding were constructed, expressed through TADS. No significant features of the accounts given by parents were excluded in these accounts.

All six cases were revealing of parents' agency, and aspects of tube-weaning not previously described, however, two cases were of particular interest, standing out as especially rich analytically, where prolonged, non-linear and multifaceted processes contrast established biomedical and clinical framings. Case 1 involved building (often in the face of significant resistance) an expansive, fluid coalition of healthcare practitioners and others to support a process that had never been tried before in the hospital involved. Case 2 focused more on anchors that were embedded in their everyday life as a family.

The following section presents excerpts from each mother's account, tracing tube-weaning from beginning to end, interspersed with commentary in the framing of TADS. The excerpts are by necessity only a fraction of the full transcripts, and they were selected to convey particularly important forms of expression, or to evidence key ideas in the interpretation. All names used are pseudonyms chosen by participants. All parents gave informed consent to participate in the study, for which ethics approval was granted by Sydney Children's Hospital Network Research Ethics Office, and ratified by the University of Technology Sydney Human Research Ethics Committee. The two parents focused on in this paper were given a draft of the transcript and invited to request any changes, including any information that may need to be removed to ensure confidentiality.

5. Findings

5.1 Case 1: Tube-weaning through expansive coalitions of expertise

Kate's daughter Jessica was tube-fed from birth until the age of 20 months. At first Jessica also breast and bottle fed. However, after a long hospital admission and many complex surgeries, Jessica left hospital aged 5 months with an extreme oral aversion, very strong gag reflex, and completely dependent on a feeding tube for all her nutrition. Jessica was initially fed via a nasogastric (NG) tube, had surgery to change this to a PEG at 9 months and then later a MicKey device (a low-profile variant of a PEG). She was fed using a pump connected to the feeding tube for up to fifteen hours per day because of prolific vomiting.

> As a mother, you want your child to eat and gain weight. The child's not interested in food because they're so full. We were living a nightmare, with a child with no interest in oral eating or drinking, managing all the logistics of tube feeding day and night, which impacted all aspects of Jessica's and the whole family's life.

Right away we see clear conflicts of motives. Kate explained that the tube was 'solving' the problem of delivering nutrition but was inhibiting Jessica's interest in food and association with food as a means to satisfy hunger. This wasn't recognised by Jessica's healthcare team, who were happy with Jessica's intake and her biomedical progress.

The process of Jessica's tube-weaning began when Kate and her family were on the beach with the feeding pump and tube. A stranger approached, saying "Oh your baby is tube-fed. Our niece just did a rapid tube-wean!". Kate immediately took a throwing action, calling the mother (from Victoria, a different Australian State) who told her that they had worked with a children's hospital in Graz (Austria) and their local children's hospital (alias CHV). The rapid tube-wean was a potential kedge anchor.

> As soon as I heard CHV, I felt this is legitimate. A centre in Australia with credibility, who would have evidence behind their method.

The involvement of CHV was important, but not enough to convince Kate. An auxiliary motive emerged to decide whether a rapid tube-wean was right for them. She took repeated throwing actions, each time finding the anchor (the idea of the rapid tube-wean) fell on firm ground. She spent two weeks reading websites and articles, especially family stories of rapid tube-weaning. Through one of these, Kate contacted another family, in her home city, who had gone to Graz for their daughter's rapid tube-wean. Kate applied a 'BRAN' test, another search action to test the ground:

> What are the Benefits, Risks, Alternatives and N is for "No thank-you". We knew our child and our instincts were that Jessica had eaten orally before and could eat orally again, but she was not hungry and had so many negative experiences around food and tubes around her mouth.

Her final throwing action involved running the idea of a rapid tube-wean past a dietician whom she trusted:

> She said "It sounds like a good idea". I was increasingly emboldened. I realised I was an expert on my child and started to back myself more. My husband's and my gut instincts were that Jessica could eat. She had a strong oral aversion but biomedically, we backed her, we knew she had eaten orally in the past and could do so again. From our research and speaking to other families, we knew she was never going to feed orally while she was so full from being tube-fed.

Having satisfied the first auxiliary motive, a new one emerged focused on making the tube-wean happen. The next action involved regaining control by enrolling Jessica's consultant paediatrician.

> So I met with our paediatrician. I had the information. I made an argument "We can't keep living like this and we know Jessica can eat again. If CHV has offered it, then our hospital needs to be able to do the same thing."

The paediatrician agreed to investigate. From the paediatrician's office, they called Tracey, a consultant child psychiatrist. Tracey knew the clinician involved in the tube-wean at CHV and made enquiries. He confirmed what Kate believed. The consultants needed to throw the anchor and test the firmness of the ground themselves. With the consultants now behind the plan, Kate was (provisionally) in control, initiating something that wouldn't otherwise have happened: "I emailed Austria, saying we're in, our team's behind us".

Graz were ready to proceed, but a stumbling block was encountered. An inconclusive swallowing test and pre-wean session had created doubt among the occupational therapist and speech pathologist in the hospital feeding team. The just-established control was at risk, but the consultants acted as advocates:

> The paediatrician backed us and backed Jessica, saying "She's fine, we'll give this a go". That confidence meant the feeding team had to get on board. They felt "This child doesn't want any food near her, how is she going to eat enough to sustain life?". They were more risk averse. The paediatrician trumped them and said "No, we're doing it". The child psychiatrist was on board. Two doctors were in our court with green lights. Others had ambers or reds, but they said "We're a go".

The rapid tube-wean was arranged in collaboration with Graz. Three other families were brought into the process – the local family Kate had contacted and two others who wanted to try the tube-weaning.

Another problem threatened to uproot the anchor. Sharing video-recordings of play picnics to the team in Graz meant sending medical information overseas, which is not normally permitted. Once again, Kate had to regain control: she reached out to a friend who was lawyer, who helped craft an email to the hospital lawyer outlining their rights, relevant rules, and collective consent. The hospital lawyer agreed to the videos being sent to Austria. Finally, actions of breaking-out or moving away were now possible, through the play picnics. These involved the four families getting together, creating a fun, playful environment in which different kinds of food were offered and shared. The rapid tube-wean established an auxiliary motive to associate food with fun for Jessica, as a means to escape the conflicts arising from to her oral aversion.

One family had a breakthrough within two days, but Jessica wasn't interested in food. Kate explained how over the coming days and weeks she was torn between wanting to continue and thinking of stopping because it wasn't working. A new conflict of motives had emerged. The Graz team reviewed the videos, saying "She's close, you see what she's not doing, we see what she *is* doing". They had noticed Jessica's glances towards food, increasing involvement in play, slight touches of food. This indication that there was in fact forward motion, however small and difficult to see, combined with ongoing support from the paediatrician, was enough to help Kate keep pulling. She stuck to the play picnics as a second stimulus.

Seventeen days in, a breakthrough arose during a multidisciplinary meeting involving the family and local healthcare team. They had talked a lot about what Jessica liked, and Kate had mentioned the bath as Jessica's 'safe place', somewhere she felt happy and secure. While brainstorming ideas the complex care nurse suggested offering food in the bath. A new means to pull on the anchor had been identified, by connecting food with water-play. That day, Kate's husband offered Jessica food while she was in the bath, and she licked the puree of his finger.

Kate described her confidence in this pulling action because it aligned with her knowledge of what water meant for Jessica. In the coming days, they transitioned from feeding in the bath to having a bucket of water beside Jessica for play while at the dining table – shifting the auxiliary means used to move away by making food fun:

> All our meals were on toy plates, and fun. We had a little pink teapot. That was part of our transition out of the bath to the dining table. We'd play with the water, and then she was eating. We were away!

This was in July. By September all tube-feeding had stopped. Jessica had successfully tube-weaned and was now completely orally fed:

> We had transformed Jessica's and our family's daily life. We had a child who would have meals with us, drink and eat, happily taste things and put them in her mouth and *enjoy* eating and all the social aspects of food.

5.2 Case 2: Preparing for tube-weaning when the time is right

Irene's son Connor fed using an NG tube from birth to 10 months, and a PEG for another two years. The PEG was anticipated for a few months while Connor had several surgeries. Irene's own words make the conflict of motives clear:

> We had to separate ourselves from what we wanted and what he needed. Intellectually I knew the tube had its purpose, but emotionally I couldn't wait until it came out.

At the point of putting in a surgically emplaced tube, Irene decided she wanted to make sure Connor would be ready to feed orally when the right time came.

> We realised the tube is going to stay for a while. It's there for nutrition. What are we going to do as parents for Connor to develop an interest to feed orally, develop his skills of coordinating food, swallowing?

From a TADS perspective, the idea of getting Connor ready to feed was an auxiliary motive that redirected her attention from the conflict.

Irene's searching actions involved asking clinicians what it would take for them to be happy for the tube to be removed. Through these, she linked the auxiliary motive with a kedge anchor: a checklist of preconditions tube removal.

> We had to tick those medical boxes. That's what I relied on Connor's paediatrician, palate team, heart team for. We can't remove this tube until Connor has proven that he can eat and eat a full diet. Does his medical team support it? Can you swallow safely? Now I have a path. Now I have a plan. I have a checklist that I can check, Connor are you achieving those things?

Irene then moved to an action of taking over, or regaining control. She separated items on the checklist: those that were delegated to the medical team, and those that were her responsibility. Irene could not control the surgeries that Connor needed or their timing. However she could shape his relationship with food. Establishing a positive relationship with food for Connor became a second auxiliary motive, one that was more exclusively within her influence as a parent.

Irene continued actions to regain control. She read blogs and networked with other parents, discovering that other children with similar cleft palate issues were eating a full diet. She said this made her think "Okay, well, it is possible", and to have the confidence to start doing things differently.

Now, actions of moving away could begin. Irene offered Connor food frequently, every day.

> It's fine going to feeding clinics and speech therapists to get guidance on how we are going to get you to feed. But you're with me daily. I have the power day in, day out, to provide you with a safe environment to give you a good relationship with food. What we do daily, that's what is going to help you eat.

Day by day, Irene pulled by offering food, helping Connor know that food goes in your mouth, encouraging him to explore textures with his fingers. Irene adjusted her own feeding practices, so that whenever Connor was having morning tea, she would also have something to eat. The firmness of ground for the anchor lay in discerning and being guided by his likes.

> We focused on Connor in terms of textures that he liked. He liked crunchy textured food. So we made a point of preparing those kinds of foods for him. Pasta was mushy and getting stuck around the top of his mouth, which wasn't a pleasant sensation for him.

Actions of moving away also involved changing family practices around choice of food at mealtimes. While Irene expected her other children to eat what they were given,

> With Connor, we had to take a step back. "If we're going to make this fun for you, we have to give you the foods that you enjoy, and that are going to support you because of the structure of your mouth."

Other moving away actions were part of established family practices, such as sitting down for breakfast, lunch and dinner together every day. Shared mealtimes became a means of forward-anchoring by enrolling Connor's siblings into practices that contributed to his familiarisation and positive relationship with food:

> We got the kids on board, going "Ooh Connor, the food is going in my mouth. Ooh yummy!" Chewing and doing all the theatrics and animation. He was captivated. Kids can do that without feeling silly.

Going out to cafés and restaurants helped Connor see others eating, another way to pull on the anchor. Connor chose what and when he ate, and exposure to joy and togetherness around food was folded into his daily experiences.

> We knew today he may not eat, tomorrow he may not eat, but in two weeks' time, we are sharing a platter of fruit, he is going to reach over and feel "I'm familiar with that, I've seen how you eat it. Oh, I know what that looks like, I know what that is, let me grab it. Then let me put it in my mouth." That was Connor, that was exactly how it played out.

Eighteen months after Connor's PEG was inserted, these repeated pulls had produced a significant change – they had moved a fair distance away:

> Connor was eating well, was very interested in food, knew that it goes in your mouth. We realised "Hold on a moment, Connor, you're eating a full diet and we aren't using the tube". Because we were so busy, we missed it.

At this point, all the medical boxes on Irene's checklist had been ticked, and they were not dependent on the tube for Connor's nutrition. However, Irene explained she didn't feel ready, and so needed to find new ways to retake control over readiness to remove the tube, which had now become uncertain again. Irene added more checkboxes to her list, linking these to a new anchor: shutting down the tube.

> Let's shut down the tube, pretend it's not there and see if we can document Connor is eating a full diet. Is he empowered, making choices about his food? Are we listening to him? I taped it down. As much as we might complain, it is an easy way to guarantee they get everything they need. So there was a lot of personal restraint on my behalf. "Irene, when the going gets tough, you've got to not use it." I gave myself a three-month window, which was realistic for me. I felt three months is enough data.

Irene explained how tube-feeding was much faster than oral feeding for Connor, so temptations to use the tube came up frequently in their busy life. Thus a new conflict had arisen, which Irene overcame by taping down the tube, focusing on the checklist, and determining a timeframe. The tape was both a physical barrier (making using the tube harder), and a sign to remind Irene of her commitment not to use it, linked to a new auxiliary motive to use the shut-down period to collect the 'data' she needed. Setting the timeframe for a review was Irene's way of taking over, regaining control over a situation that had once again presented an uncertain horizon. The checklist continued as a kedge anchor, now expanded with new features focused on Connor's eating and choices about food, showing the tube would not be needed when Connor got sick, and that he could take medicine orally. Over the three months, Irene got nearly all the 'data' she needed, except Connor had not get sick. Now the conflict swung back to one relating to the tube's removal, rather than the temptation to use it:

> I wanted to remove it. How much easier would life be without it?! I wanted to take it out. I just felt we didn't have enough data, I wasn't confident to remove it because he hadn't gotten sick and I hadn't used any medicine. So I didn't think that was the time to remove it.

Irene decided to review the situation on a monthly basis. This was another action of taking over, regaining control over the uncertainty of waiting for the opportunity to arise to take the pulling actions of testing the need for the tube when Connor got sick. After two months, Connor got sick with croup, and they did not need the tube. Shortly after he had a slight fever, and Connor swallowed some medicine orally.

> Okay, there's my data. There's my evidence. We ticked all the boxes. So that was a great big box to tick. I was in the headspace "Now we'll take it out, I'll just decide when and I'm really just relying on a sign of when".

The kedge anchors of the checklist and shutting the tube down had served their purpose. Irene had converted her auxiliary motive to develop a positive relationship with food into actions that pulled forward.

However, Irene was not yet ready. She contacted her Connor's medical team for advice about removing the tube and prepared a tube-removal kit. With this action of regaining control, she knew *how* to remove the tube, but was still unsure when to do it, due to doubts from various sources. A new conflict had emerged: medically, Connor was ready and people around Irene were querying why the tube was still in place, but she and her husband were worried about removing it prematurely.

Irene regained control by explaining the tube removal process to her husband, and seeking his support for her decision to wait until she was certain the time was right. This decision did not specify how that certainty would arise but it did establish an auxiliary motive to wait until the moment came.

> What happens if I take it out and then I regret it? That was playing on my mind. That's where I said "Irene, when you do it, you've got to feel 100 per cent and you've really got to rely on that feeling and that time". I completely shut out those pressures and made them irrelevant. It brought clarity for me and I could completely be in tune when it felt right.

This situation persisted for a couple more months. What might look like 'passive waiting' can be interpreted within a TADS framework as actually part of moving away – of agency – distinctive for its pulling towards the unknown. Without warning, the time came:

> The day we removed it, we had no inkling. It wasn't any different. We went to bed, Connor was fast asleep, and I said "Right, it's the time. We're going to take it out". And I did. It was such a clear moment, clear as day. Now or never. I had everything ready, I felt empowered, I felt equipped, I felt it was right.

The physical removal of the tube took less than two minutes. Connor slept the whole time, and the tube hole was closed by morning, when he ate his breakfast as normal.

6. Discussion

In light of the two cases, this section discusses how TADS provides a valuable, new alternative to biomedical and clinical framings of the struggles encountered in transitioning from tube to oral feeding. It also critically reflects on the metaphor of forward anchoring and explores how these cases extend this notion as a relatively recently development within TADS.

6.1 A different understanding of the problem and solution

Difficulties with tube-weaning are often considered in biomedical terms (eg. Wilken et al., 2018), but this narrows the gaze on presumed deficits in the child, overlooking the social aspects of learning to feed orally. The problem of tube-weaning has also been addressed from a clinical perspective, highlighting insufficient hospital-based tube-weaning programs, absence of tube-exit strategies (Edwards et al., 2017; Syrmis et al., 2020; Tilyard et al., 2020) and uncertainty among clinicians understandably concerned about risks to children's health (Dovey et al., 2018; Lively et al., 2019; Syrmis et al. 2020). These are pressing problems, but the clinical framing again pushes parents to the side, even when parents are known to have such a significant influence on children's feeding (Daniels, 2019). Parents are frustrated when information about tube-weaning is not shared with them by clinicians (Syrmis et al., 2019; Hopwood et al., 2020; Dadich et al., 2021). TADS does not displace or replace biomedical and clinical concerns, but connects these into an understanding in which parents' crucial agentic contributions are recognised. This repositions parents, not as outsiders to the child's deficient body, or on the margins of care, receiving (or not) information provided by clinicians, but as central to complex processes.

Biomedical safeguards and clinical expertise were not dismissed in these processes. Irene delegated judgements as to Connor's biomedical readiness for tube-removal to the clinical team. The problems she took responsibility

for were not in the clinical realm, but rather at home. Kate's story is one of establishing coalitions of expertise, including many clinicians, parents and others. Kate and her husband contested assumptions made about Jessica's bodily functions and ability to learn to feed orally. Those assumptions pinned the gaze to the present, while Kate enrolled clinicians into an alternative that committed not to what Jessica could do today, but to what she could do tomorrow. A TADS view of the struggles in tube-weaning does not compete with established views, but accommodates them within a broader, more inclusive framing that better recognises the role played by parents.

One challenge is that they has so many causes (Goday et al., 2019; Hopwood et al., 2020; Hopwood, Moraby et al. 2021). This can make it difficult to understand challenges of tube-weaning, risking of reductionism (overlooking important specificities of each case), or relativism (the process will be different in every case). Despite very different approaches to tube-weaning, the TADS framework provide a common basis to understand the dynamics of change in each case. Table 1 summarises them in relation to conflicts of motives, kedge anchors, and the three kinds of actions associated with forward anchoring (Sannino, 2020b). The deeper gaze afforded by TADS reveals the same dynamics of change underpinning what appear to be different processes.

TADS also expands our view of what might help families wanting their child to feed orally. This begins with recognising the core conflict of motives (need for tube vs desire to feed orally), because this triggers the establishment of auxiliary motives, which can radically reframe the situation – as for Kate – from one fixated on biomedical risks of oral feeding and clinical comfort with the status quo, to one fixated on making oral feeding possible (Table 1). Auxiliary motives can also reframe the situation for parents like Irene from one of waiting on the sidelines while clinicians do their work to one of contributing actively to establishing the conditions for oral feeding (Table 1).

Stopping tube-feeding is often harder than starting it (Forbes & Grover, 2015). A key reason for this pertains to the uncertainties of tube-weaning, which are challenging for clinicians and parents (Hopwood, Elliot et al., 2021; Lively, 2019). TADS reveals how security can be established despite the pathway and destination being unknown. Actions of searching and regaining control give those involved confidence to move away from the status quo, towards a tube-free future. Table 1 shows these may vary considerably, suggesting that diverse means to escape the conflicts of tube-dependency may be available, provided those involved know what is needed. Through TADS we can identify questions that might guide parents and clinicians working towards oral feeding: How can we check the ground is secure (searching)? How can we bring this into our realm of influence (taking control)? How can we move away, however tentatively and incrementally, from the status quo? These transform the distant and uncertain question of safe oral feeding into proximal questions. The TADS view does not simply hand over responsibility for tube-weaning to parents, but it does show how, as primary caregivers for children, and as brokers of their access to the healthcare system, they can be instrumental in driving change. This is why TADS, an alternative to the biomedical and clinical framings that highlights parents' agency is so important.

6.2 Critical reflection on TADS and conceptual advances offered

One might ask whether a complex framework such as TADS is needed. In response, we highlight how the criteria applied to concepts of TADS were upheld in the analysis, suggesting that its specifications are indeed relevant and crucial to understanding dynamics of agency in such situations. Consider first TADS' central basis in conflicts of motives. What is gained by framing issues of tube-weaning in this way? This overcomes problems of biomedical or clinical framings, and goes deeper as it taps into understandings of the dynamics of agency more generally. Jessica's and Connor's stories be understood on common terms that nonetheless discern important differences, and can be linked to other stories – of feeding in everyday parenting (Hopwood & Gottschalk, 2022), and indeed of work on homelessness (Sannino, 2020b). This enables us to unlock our gaze from the problem (feeding tube, child's body, absent clinical guidelines, poor communication) and instead focus

on the solution. The strict focus on conflicts of motives, associating agency with becoming unstuck is fundamental to the new insights into tube-weaning discussed above.

What of the need to distinguish anchoring forward from anchoring-backward. As explained above, Sannino (2020b) reserves the identification of auxiliary stimuli as kedge anchors for those instrumental in the elaboration of new meaning. Novelty, new sense-making, interaction and experimentation were at the heart of the two cases. While neither involved inventing new clinical procedures for tube-weaning, both depended on finding new ways to interpret uncertain situations. These started from seeing tube-weaning as possible rather than impossible, and expanded through new meanings around play, siblinghood, adult snacking, visits to cafés, and so on. Both processes were not a matter of following a procedure (although procedures were part of both cases), but rather processes of trying, monitoring, reviewing, adjusting, and trying again or trying something different. This is precisely the experimentation that Sannino (2020b) inflects in the metaphor of forward anchoring into the unknown.

TADS places a view of agency as at the intersection of individual and social within our empirical grasp. An account of either transformation that evacuated the contributions of Kate and Irene would clearly be inadequate. However, these contributions were contingent on the contributions of others (other families, professionals, other family members) and use of cultural tools (checklists, video recordings, toys etc.). These were agentic projects *with* others and the world (Cole et al., 2019; Sannino & Engeström, 2018). Kate's and Irene's roles can be recognised without falling into traps of individualism.

This paper is among the first to explore forward-anchoring as a feature of TADS in 'wild' contexts outside of researcher intervention. Although guided clinical processes were important, many cultural means and actions associated with them were very much grounded in everyday life and practices: a spontaneous meeting on a beach, reading blogs, adjusting family meal practices, visits to cafés, baths, water play. Forward anchoring was happening here with no researcher facilitating the process – suggesting it to be an authentic metaphor for double stimulation in the wild, and opening up questions about where else this might be happening, what forms kedges might take, and what actions might be used to pull on them. Taking up the metaphorical expansion around actions of searching, regaining control and moving away, the analysis showed that these can unfold in recursive fashion. Some movements might beget the need for more searching, while disruptions or doubts can demand new actions to regain control. The metaphorical movement of a ship can easily accommodate a process that involves throwing, taking over, and breaking-out as recursive rather than strictly linear.

However, the metaphor strains somewhat in relation to two other features of forward anchoring highlighted here. One pertains to who is doing the pulling actions, and who those actions connect with. The ship metaphor suggests a relatively stable, confined group of people. However, both cases involved expanding constellations of people. The metaphor does not obviously point to actors who might resist, pulling the other way, or unsettling the anchor from the bed, yet these featured in both cases described above. Secondly, it seems obvious that those on a ship would be able to throw an anchor and pull on it. However, the actions of searching, regaining control and moving away cannot be taken for granted or assumed to be within parents' and others' reach, and can themselves be destabilised when new conflicts emerge. All metaphors have their limits, and these considerations do not undermine the value of forward anchoring as part of the wider conceptual apparatus of TADS. Indeed, important insights were reached precisely by attuning the analysis to this metaphor.

7. Conclusion

Tube-feeding in childhood has significant negative impacts on the child and their family. The challenges of weaning from a tube to oral feeding are often framed in biomedical or clinical terms, which focus on the known present rather than the unknown future, and overlook the crucial role parents play in children's learning to feed orally. New ways of understanding the dynamics of change from tube- to oral feeding are needed, which

recognise weaning as something that is often accomplished through significant struggle, requiring those involved to commit to a desired but uncertain future, the pathway to which cannot be known in advance.

Transformative agency by double stimulation (TADS; Sannino, 2015b) offers a basis to develop precisely such an understanding. It does not displace biomedical and clinical concerns, but rather incorporates these alongside complex social interactions and cultural mediations in which parents play a crucial, agentic role. This role is not one of isolated individuals, but one that may involve reaching out to and enrolling others, acknowledging individual contributions without shrinking from their social contingency and consequences (Nardi, 2017; Stetsenko, 2020a). Recognising conflicts of motives at the core of this, and emerging as the transformation unfolds, is key to understanding why so many families can get stuck in tube-feeding, but and to understanding the ways of becoming unstuck.

As part of an upsurge of interest in agency from cultural-historical perspectives (Stetsenko, 2019), the paper has focused on the metaphor of forward-anchoring, recently added to TADS (Sannino, 2020b), and unexplored in 'wild' settings of everyday life. Analytically specifying kedge anchors as second stimuli that elaborate new meanings to support transformative actions where there are no known solutions (Sannino, 2020b) provided a basis to empirically grasp how parents – with others – made significant change for their children and families possible, realising futures that were otherwise deemed out of reach, through multiple, recursive actions of searching, regaining control and moving away. Although the metaphor strained in relation to some empirical features, it nonetheless proved highly valuable in elucidating the dynamics of agency, helping to reveal the radical potential of double stimulation in everyday life. From being consumed with the difficulty of tube-weaning, we can approach it in terms of what has occupied four generations of activity theory (Engeström & Sannino, 2020: a matter of emancipatory possibility of seemingly small actions, of collectively securing alternative fates, of negotiations and deviations as people bring different expertise to bear in changing constellations of actors, and of enacting a utopia – in the sense of making something desired but seemingly impossible come to pass.

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