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Restoring balance: How consumers orchestrate family care following unplanned disruption

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Biographical note

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How do consumers orchestrate multiple and complex practices of care when faced with unplanned disruptions to their lives, such as chronic health conditions? We conduct a qualitative study of families where a child was diagnosed with Type-1 diabetes. Inspired by a dance metaphor, we explain how families (1) gather materials for movement, (2) link movements into phrases, and (3) develop an orchestrated style of care as they sense and respond to the dynamic requirements of caregiving when faced with insufficient or unfeasible market solutions. Adding this new perspective to the managerial view used by prior consumer research on family care, we propose an extended perspective on care, which better accounts for how families search to restore life balance in challenging circumstances. This extended perspective illuminates new aspects of consumer engagement with paid and non-paid service providers, and opens avenues for future research in the domain of family care.

Keywords: family care; family management; orchestration; dance; chronic health condition

Statement of contribution:

This paper goes beyond managerial accounts of family care to account for dynamics that transcend moments of decision-making and tension management, creating empathy in consumer researchers about the ways families work and make decisions. We develop an extended perspective to care that does not deny the embeddedness of families and its members in consumer culture yet acknowledges the limits of the market to assist families in the daily unfolding of complex practices of care.

> On the morning of the third day [after my son Pâris was diagnosed with Type-1 Diabetes], I still felt like I was in a state of shock. I slipped out of bed while Pâris was sleeping and stood looking at myself in the bathroom mirror. And something happened. I felt the power of life striving to lift my heart up. I quietly turned on some music and started dancing. Then I looked down and there was Pâris smiling up at me. He was dancing too. Suddenly I understood: all I had to do was to take care of one moment, one day at a time. So, we kept on dancing.
>
> – Wendy Mangeant, Safely in the Rainbow, documentary

Introduction

A considerable body of work in marketing and consumer research has examined the issue of caregiving in families (Barnhart & Peñaloza 2013; Barnhart et al., 2014; Epp & Price, 2018; Epp & Velagaleti, 2014; Huff & Cotte, 2010, 2011; Piacentini et al., 2014). These studies employ a managerial perspective of care, emphasizing the management of emotions, roles, and activities in caregiving. As such, this perspective privileges problem solving, decision-making, resource utilization, the formation of caregiver–receiver partnerships, action planning, and self-tailoring (Lorig & Holman, 2003) as important aspects of care within families. Arguably, this managerial perspective assumes that caregiving operates under the logic of choice (Mol, 2008), which privileges consumer agency (Epp & Velagaleti, 2014) and explains care as the sum of a series of decisions, as well as the planned adoption and subsequent habituation of care-related practices (Thomas & Epp, 2019). Such prior research has addressed the challenges of assisting vulnerable family members in consumption activities (Barnhart & Peñaloza, 2013) and has discussed how managing care is critical to integrate family members who are unable to consume independently (Barnhart & Peñaloza, 2013; Dean, Kellie, & Mould, 2014; Pavia & Mason, 2012).

However, current research does not fully unpack a less visited facet of caregiving, one that is less strategic, yet more fluid and creative, as it involves sensing

and responding to the dynamic requirements of complex care. Uncovering these fluid and creative aspects of caregiving is important for marketing and consumer research because doing so advances our understanding of how families address complex care needs when careful planning and outsourcing are insufficient or unfeasible, and enables researchers and policy makers to adopt an extended approach to caregiving in families. Only when accounting for both facets—the managerial and the fluid and creative aspects of caregiving—will we be able to design, organize, structure, and deliver care solutions to families in ways that integrate market and non-market resources.

To address this oversight in consumer research on caregiving in families, we address the following question: How do consumers orchestrate multiple and complex practices of care when faced with unplanned disruptions to their lives—such as a chronic health condition—for which market solutions are often not readily available? A chronic health condition (CHC) represents an extreme context in which to examine the orchestration of care in families because CHCs extend indefinitely, and their evolution depends in part on how care is delivered and received (Barnard, Lloyd, & Holt, 2012; Gregory, 2005; Kepreotes, Keatinge, & Stone, 2010). We address these issues through a qualitative study, including interviews and archival data, on the experiences of families living with Type-1 diabetes (T1D), a CHC affecting mostly children and young adults. In developing our contribution, we engage with the literature at the intersection of studies on family consumption and on caregiving.

Inspired by the metaphor of dance, we conceptualize caregiving as orchestration (which comes from the Greek *orkheisthai*, meaning 'to dance') to account for the constant movement enacted by caregivers/orchestrators in search of balance, a movement that is amplified under disruptive life circumstances. As the opening quote illustrates, care orchestrators may feel that they must move—and keep on moving—to

continuously address their family's needs for care. Accordingly, we theorize the orchestration of care as a non-linear and dynamic configuration of practices of care which overlap and intersect, as dance movements forming different arrangements, which are then linked by the orchestrator in a complex dance. As with dance, the orchestration of care alternates between anchoring movements—practices fully immersed within families' daily routines and challenges—and aerial movements—those actions through which families transcend their life circumstances—building upon a momentarily achieved balance to innovate in creating value for themselves or others. Furthermore, we hold that, under unplanned disruptions, as families collectively enact the sophisticated dance of the orchestration of care, one caregiver emerges as the key orchestrator who, sometimes strategically but often instinctively and invisibly, encourages other actors to engage with the dance and supports the adoption and habituation of new practices of care (Thomas & Epp, 2019).

We also contribute to the understanding of work that consumers do in the family domain (Cappellini, Marilli, & Parsons, 2014; Epp & Price, 2008; Epp & Velagaleti, 2014; Huff & Cotte, 2013a, 2013 b; Piacentini et al., 2014). We introduce the notion of 'care orchestrator,' which is aligned with prior research, to highlight the invisible work of consumers who care for others in family contexts. Yet, extending prior understandings, our conceptualization acknowledges the limits of consumer agency when life is disrupted, creating empathy in readers and consumer researchers about the ways families work and make decisions under these circumstances. Consequently, this extended understanding of caregiving highlights the limitations of a managerial view that privileges decision-making processes and the distribution of care-related tasks and resources.

To further discuss our research, the article will follow this structure: First, we offer a brief overview of the interdisciplinary research on family consumption and caregiving, discussing how orchestration has been addressed at the family level, particularly in the context of CHCs. Next, we introduce the research methods and context of this study, followed by the findings, which are organized into three phases; each phase maps the key aspects involved in the orchestration of care as dance. Finally, the discussion shows how the metaphor of dance complements the managerial perspective to offer an extended perspective on care that extends subject knowledge for researchers and practitioners alike.

Literature review

On care and consumption: a managerial perspective of the orchestration of care

Consumer research has covered a variety of coping strategies and identity narratives that individuals embrace to combat an illness, to enhance the chances of cure, or to improve well-being during disruptive circumstances. This stream of literature is individual-centric (i.e. focuses on self-care/ self-management) and addresses the adoption of a fresh start mindset by consumers (Price, Coulter, Strizhakova, & Schultz, 2017; Whitehead 2018) to overcome challenging circumstances, past or present, such as developing healthy eating habits to manage food-related health risks (Cappellini et al., 2014; Kristensen, Askegaard, & Jeppesen, 2013). Pavia and Mason (2004), for instance, show how individuals experiencing life-threatening situations make purchases and engage in experiences which reflect their beliefs about their future and their recovery trajectories. By connecting consumption with individuals' capacity for self-care, these studies present self-care from an agentic individual's perspective, suggesting self-care as being essential for achieving resilience in life and for pursuing projects of identity

reconstruction and transformation.

In parallel with this account centred on individual agency, consumer research on family dynamics shows that the intersection of care and consumption has an important collective facet (Piacentini et al., 2014; Thompson, 1996). Having the family as the key focal collective, researchers have examined the challenges involved in 'doing family' (Epp, Schau, & Price, 2014) and have shown that a multiplicity of actors cooperate and interact to constitute and preserve family well-being (e.g., Dean et al., 2014; Kerrane, Bettany, & Hogg, 2014; Piacentini et al., 2014; Thompson, 1996). This line of research has shown how disruptions such as health concerns and changes in living arrangements interfere with family life, producing unintended and often long-lasting lifestyle challenges (Pettigrew et al., 2014; Price & Epp, 2015).

Disruptions arguably heighten the need for family care, as noted in Epp et al. (2014), who discuss the efforts made by family members to preserve family practices across long-distance relocations. As the demands on family care surpass the capacities of any one individual, the integration of other family members, support networks, and external service providers is required (Barnhart et al., 2014; Huff & Cotte, 2013a, 2013 b; Epp & Velagaleti, 2014). Perceptions of urgency, lack of nearby kin, and the rising standards of parenting determined by the market (Bradford & Theresa, 2010; Clarke, 2007; Epp & Price, 2008, 2010; Epp & Velagaleti, 2014; Huff & Cotte, 2013b, 2013c) drive consumers to outsource care beyond family boundaries.

Families seeking market support for caregiving often assemble complex networks of consumption (Barnhart et al., 2014; Epp & Velagaleti, 2014). For instance, Barnhart and Peñaloza (2013, p. 1113) have shown that when elderly family members face 'physical and mental limitations that impair their ability to perform everyday consumption activities,' consumption becomes a group matter rather than an individual

one. To keep their consumption-related activities and preserve their sense of identity, elderly family members often need support from a collective and dynamic care network, which Barnhart and Peñaloza (2013) call the elderly consumption ensemble (ECE). In introducing this concept, Barnhart and Peñaloza (2013) note the level of improvisation that is needed in an always-changing configuration of caregiving actors and the care practices they perform. Although they acknowledge the relational and often unpredictable nature of caregiving within families, their work does not fully explore the constant collective sensing of and response to this instability, focusing instead on the outcomes of caregiving (e.g. constrained consumer agency, old identity) for the elderly. Similarly, Huff and Cotte (2012) highlight the challenges that arise when adult children outsource care for their elderly parents to paid service providers. Rather than exploring the continued relational work of orchestrating care, though, they focus on the 'cycle of major and minor decisions as various care services are chosen, used, and then deemed inappropriate' (p. 640)

Epp and Velagaleti (2014) refer to assemblages of care to discuss how parents bring together market and non-market resources to provide the best care for their children. Assembling care thus requires the selection and recruitment of a wide array of paid care providers, negotiating multiple discourses and placating tensions that emerge when actors interact in the assemblage (see also Barnhart et al., 2014). As Huff and Cotte (2013a) note, tensions, stress, and complexity are heightened when parents' choice of paid care providers or access to alternative options of care is constrained. This prior research is based on contexts where consumers are usually able to discuss and plan their caregiving practices ahead of time, even when their agency is limited (e.g. unplanned pregnancies, which allow to-be parents a few months to discuss and decide on childcare alternatives). Conversely, in the case of unplanned life disruptions, such as

the diagnosis of a CHC, decisions must be made on the move as consumers have no choice but to immediately engage in new practices of care while under stress.

Consumer research has considered how families adopt and become habituated to new practices of care (Mason & Pavia, 2006; Pavia & Mason, 2012; Thomas & Epp, 2019) and how they adjust existing practices when life is disrupted (Epp et al., 2014). Life-disruptive circumstances, such as unexpected widowhood, bankruptcy, natural disasters, or the diagnosis of a CHC, are particularly challenging to adapt to. In fact, research has shown how families whose lives have been disrupted by unplanned circumstances strive to normalize life by orchestrating activities that cut across their world and the 'normal world' (Morse, Wilson, & Penrod, 2000). However, these families acquire an 'outsider' status and are marginalized in several markets (Mason & Pavia, 2006; O'Malley & Prothero, 2006) because their uncertain lives make having traditional consumer trajectories unlikely.

In discussing how families adapt when the need for care is exacerbated due to one of the children's disabilities, Mason and Pavia (2006, p. 1012) start out with the understanding that 'families with special needs children are undergoing significant transition and attempting to create an optimal, ongoing level of functioning for the family system.' In this context, families adapt roles and norms as well as rituals and identities to make it easier for them to interact in the non-welcoming marketplace. Mason and Pavia (2006) point to their concerns about the long-term emotional and psychological impacts on family members from constantly adapting to meet caregiving demands. This research is particularly helpful for consumer researchers in acknowledging that families adapt and juggle to address the demands of care and to negotiate their caregiving needs when the market fails to serve them. However, because it focuses on the marketplace as the baseline and considers consumers as agentic and

strategic individuals searching for marketplace inclusion, this approach falls short of capturing the ways in which families deal with the limits of the market in the daily unfolding of complex practices of care.

Thus, prior research has shown that, in the context of caring for family members who require constant family support, caregiving is a collective challenge which resembles the management of an enterprise that implicates family members and service providers, and requires problem solving, decision-making, optimization of resources, planning, and adaptation (Lorig & Holman, 2003), all of which have long-term repercussions for the family (Ersig, Tsalikian, Coffey, & Williams, 2016; Larson, 2000).

Extended family and market actors form a system of supportive actors for patients with CHC (Ryan & Sawin, 2009). Decisions are made, problems are solved, resources are distributed, and patients and their families adapt to the circumstances, planning whenever possible. Still, a large portion of the orchestration of care in such contexts is achieved through fluid, unpredicted, and creative movements demanded by the never-ending, non-linear, and dynamic configuration of practices of care within families. Extant consumer research does not fully account for these aspects of caregiving in families.

Towards an extended understanding of orchestration of care

Although the term 'orchestration' has been applied by consumer researchers to describe carefully planned activities within a family (e.g. Epp & Price, 2008), research focusing specifically on orchestration of care is nascent in consumer research. Hence, we draw from the more consolidated perspective of orchestration in occupational therapy (Backman, 2004; Larson, 2000).

Orchestration in occupational therapy is defined as complex daily activities that are central to facing disruptive challenges and to sustaining family lives and personal relationships at the family nucleus, and which require daily 'anticipation, forethought, shifting of information, decision-making, and a coordinated response' (Larson, 2000 p. 270). Care orchestrators are family members who assume the role of lead caregivers. They are emotionally involved with the care receivers and inspire, support, and energize other actors in the care system (Larson, 2000).

In this research tradition, orchestration is also concerned with 'the need to attend to the rhythms of daily life, most particularly, balanced participation in […] work, play, rest, and sleep.' (Backman, 2004, p. 202). Similarly, Larson (2000) argues that '[l]ike playing music or dancing, daily rounds are arguably rhythmic and cyclic, and desirably arranged to maximize harmonious occupational engagement' (Larson, 2000, p. 206). This understanding of orchestration resonates with dance as a metaphor to understand the orchestration of care—in dance, practices emerge, are embodied, and create meanings to produce a dynamic arrangement as dancers search for balance (Muller & Ladewig, 2013).

Metaphors can be used to create new ways of viewing phenomena, offering supplementary or even contradictory approaches to the analysis (Morgan, 1980). Seeing orchestration as dance is relevant because it helps in explaining how families 'dance to the music,' or, in other words, how they rearrange everyday life after unplanned disruptions by performing coordinated sequences of care practices (which could be likened to dance phrases). In this dance, caregivers sometimes strategically, but often instinctively, create daily routines that include rest and inactivity. These periods of rest give their dance structure, while also determining the time signature and tempo of their lifestyles and those of other family members (Larson, 2000).

By employing dance as a metaphor, we are invited to see the orchestration of care in families not merely as a sequence of decisions and negotiations, but as a never-ending dance in pursuit of balance. Seeing orchestration as dance requires two basic assumptions:

1. A dance is an arranged sequence of phrases, which are, in turn, a sequence of movements. In the context of a CHC, a dance is a sequence of practices of care (e.g. maintaining adequate insulin levels, nurturing a child), which involve several actions (e.g. measuring glucose levels, calculating carbohydrates, injecting insulin; or explaining symptoms, comforting the child, planning family vacations).
2. A dance is a pursuit of balance (Muller & Ladewig, 2013). In the case of orchestrating care for a CHC patient, the pursuit of balance requires orchestrating not only work, but also play, rest, and sleep, known as phrases and pauses in dance. Accordingly, this study considers practices of care in an extended sense to include not only symptom management and disease treatment actions but also the building and sharing of knowledge, and the addressing of family members' emotional and relational concerns, among other practices that allow patients and their families to continue navigating life with a CHC (Mol, 2008). Orchestration involves sensing and responding to environmental stimuli, just as in a dance (LaMothe, 2015). What balance means differs for each family, just as it differs for ballet (a static centre of the body) and tango (a good connection to the ground) or other dance styles (Muller & Ladewig, 2013).

In sum, the term orchestration used in this work extends prior consumer research (e.g. as a metaphor for the careful planning of family practices in Epp and Price (2008)

and the distribution of labour in the household in Cappellini et al. (2014)) to account for the newly advanced dance perspective on the phenomenon.

Mol (2008) argues that 'the logic of choice', which we see as guiding managerial approaches to care, acknowledges yet does not fully explore the continuity and instability of care, which she describes as 'the logic of care.' As Mol (2008, p. 52–53) notes:

> [B]alance is important […], but not as a matter of adding and subtracting advantages and disadvantages. After all, addition and subtraction require fixed variables, but in the logic of care no variable is ever fixed. All variables are variable—to some extent. The 'balance' sought, then, is something that needs to be established, actively, by attuning viscous variables to each other. Rather than the balance sheet of the accountant, the balancing body of a high-wire artist or a dancer come to mind. And even if finally, everything fits, if everything is nicely attuned to everything else, it may all fall apart again. Your fingers lose their sensitivity. Your eyesight deteriorates. You have to care for your aging parents. Your relationship falls apart. You are made redundant at work. You want to take a long-haul flight across several time zones: how do you manage that? The logic of choice suggests that choosing is confined to specific moments. Privileged moments, difficult maybe, but bounded. The logic of care, by contrast, suggests that attuning the many viscous variables of a life to each other is a continuing process. It goes on and on, until the day you die.

As an anthropologist and philosopher, Mol (2008) offers a critical view of health care as a market and patients as consumers. She opposes the 'logic of choice' to the 'logic of care' and argues for the latter to prevail. We, in contrast, note that the logics of choice and care, albeit contradictory in many ways, are not mutually exclusive. Rather, they coexist in the lived experiences of families who care for members affected by chronic health conditions. We propose that advancement can be made by seeing family care from an extended view that does not deny our embeddedness in consumer culture,

yet acknowledges the limits of the market to assist families in the daily unfolding of complex practices of care.

Research context

CHCs are illnesses that last for at least one year and produce sequelae of 'limitation of function, activities or social role [and] dependency on one or more of the following: medications, special diet, medical technology, assistive device, personal assistance, and the need for medical care or related services' (Stein, Bauman, Westbrook, Coupey, & Ireys, 1993, p. 344–345). As CHCs persist, they require extended care, producing alterations in the family arrangement that may be fundamental and permanent (Barnard et al., 2012; Gregory, 2005; Kepreotes et al., 2010).

The diagnosis of a CHC comes with the understanding that these conditions are often incurable. There is uncertainty, though, regarding a CHC's potential progression, symptom burden, and psychological impact because these factors depend on the practices of care that are adopted and how they are habituated. While some CHCs may be more limiting or serious than others, many can be effectively dealt with by adult patients in the normal course of their lives. It is when a CHC affects children, as is frequently the case with T1D, that the need for family support—and the impact of the condition on family dynamics—becomes more evident (Kepreotes et al., 2010).

A T1D diagnosis is an unplanned disruption to family life as it includes a series of symptoms that may result in urgent hospitalization. In T1D, the body's immune system destroys the insulin cells, eventually stopping insulin production in the body. Without insulin, blood cells cannot absorb sugar (glucose), which they need to produce energy (Barnard et al., 2012). Diabetes can be a complex CHC if it is not treated early and rigorously. If cared for, it becomes another layer in the otherwise 'normal' lives of those who experience it (Babler & Strickland, 2016).

Nevertheless, even after a certain degree of normalization is achieved, dealing with a CHC is a demanding task. For individuals with a CHC, the line between being sick and being fully able to participate in society is completely blurred; hence, 'the disease unavoidably gets entangled with the practicalities and the complexities of everyday life' (Storni, 2014, p. 1443). What further complicates the situation is that care practices and solutions that promote quality of life for CHC patients and their families only work temporarily because constantly changing bodies mean that the disease is never the same (Mol & Law, 2004).

Materials and methods

This study focuses on families with one dependent member diagnosed with T1D. We conducted 15 interviews in all; 13 interviews with members of 8 families and 2 in-depth interviews with specialized nurses. The nurses worked at an NGO supporting families dealing with T1D as well as at a private school in Santiago, Chile that several children with T1D attend.

Interviews were conducted in person, in Spanish, by one of the authors, or a trained research assistant, who is also a T1D adult patient and a volunteer at an NGO supporting families dealing with T1D. This overlap resulted in excellent rapport with the participants. The interviews lasted 68 minutes on average, corresponding to 276 pages of single-spaced transcribed text. The quotes included in this paper have been translated by the authors, who are proficient in both languages, and participants' names have been replaced by pseudonyms (Table 1).

Table 1. Interviewee information.[1]

Interview number	Interviewee's Role	Interviewee (Pseudonym)	Patient (Pseudonym)	Patient's age at diagnosis	Patient's current age
1	Mother	Carolina	Fernanda	4	10
2	Mother	Elena	Magdalena	9	11
3	Mother	Ana Maria	Jacinta	6	7
4	Father	Joaquín	Cristián	19	24
5	Patient	Cristián	Cristián	4	18
6	Mother	Marina	Cristián	4	18
7	Mother	Susana	Alvaro	10	18
8	Patient	Alvaro	Alvaro	10	18
9	Mother	Paula	Bruno	16	18
10	Father	Javier	Bruno	16	18
11	Patient	Bruno	Bruno	16	18
12	Mother	Barbara	Paloma	6	15
13	Father	Diego	Paloma	6	15
14	Nurse	Kamila	N/A	N/A	N/A
15	Nurse	Julieta	N/A	N/A	N/A

[1] Other mentioned persons in paper that are not in table are also pseudonyms.

Data analysis showed mothers to be the lead caregiver and care orchestrator in all families, a finding that is consistent with previous research on family care (Graham, 1983). Mothering practices, however, involve negotiations with other actors, including fathers, children, and a wider social network (Rojas-Gaviria, Cardoso, Scaraboto, & De Araujo Gil, 2019). Thus, to capture the multiplicity of views on familial caregiving, our data collection also included fathers and adult patients.

The interview dataset is complemented by archival and online data from a wide array of sources (e.g., media, websites, blogs, official documents, historical documents, and a documentary made by a family with a T1D member). Some secondary data sources (e.g., magazines from the Youth Diabetes Foundation of Chile [YDFC]) include first-hand narratives by diabetic patients and interviews with families of diabetes patients, providing data that is about as rich as that obtained through interviews.

Data analysis entailed a careful reading and an emergent coding of the dataset by all authors. Next, we examined the dataset for patterns, using the guidelines recommended by Thompson, Pollio, and Locander (1994). The first round of data analysis began with collecting archival data and involved iterations between the data and relevant theories, while leaving room for unexpected theorizations to emerge. Next, sensitized to Mol's (2008) perspective on care, we re-coded the dataset and developed an interpretation of how families orchestrate care. Finally, we engaged with the dance metaphor in a final round of analysis. In presenting our analysis to individuals who have a T1D patient in their family, we received feedback that these findings resonate with these consumers' own experience or understandings of caregiving in the context of the CHC.

Findings

Participants concurred that a T1D diagnosis immediately puts family life on hold. As

the flow of insulin from the child's pancreas stops, so does life as they know it. At this early stage, patients and their families often cannot comprehend what is happening to them, and many expressed fear and anxiety as they came to understand diabetes as a chronic and life-threatening condition.

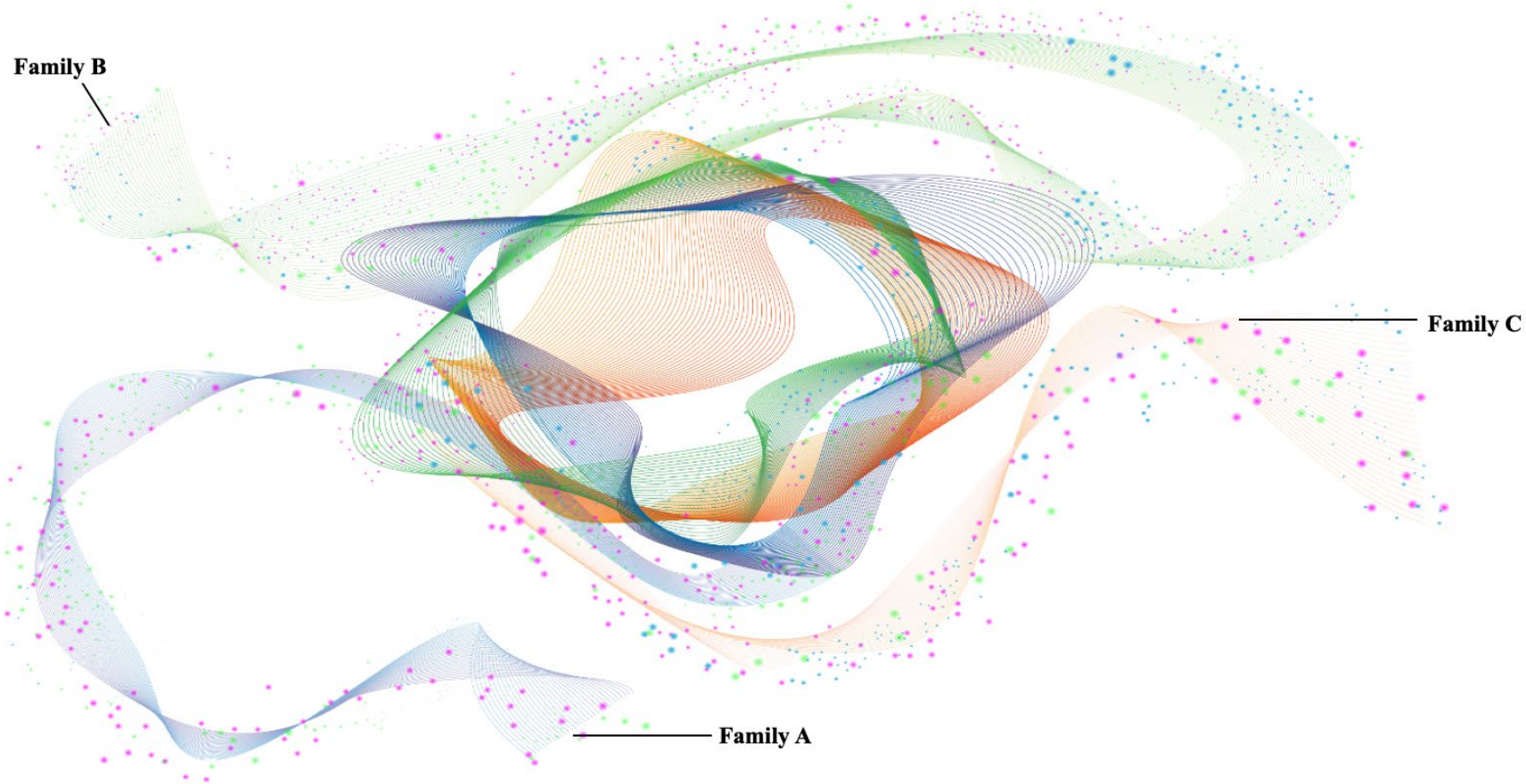
Diagnosis is often a result of hospitalization. Not able to continue with its natural course of action, the family dissolves into the system of professional medical care. Our participants felt they lacked control over their children's and their own lives. Many recalled being 'in the dark,' letting medical professionals select a course of treatment and impart basic knowledge about T1D.

Procedures for measuring glucose levels, injecting insulin, controlling food intake, and identifying symptoms of hyper and hypoglycaemia keep the family moving as they need to be immediately learned and implemented. There is no time for planning, thinking, choosing, or organizing. Yet, from the beginning, family members feel and connect to each other through their sentient bodies. The fear of having something of earth-shaking proportions occurring to a family member is followed by pain, grief, sorrow, and sadness. Courage is required to move forward, and it will lead the families to the beginning of an enduring dance.

In the following sections we demonstrate how the orchestration of care unfolds as an enduring dance, which we describe in three phases: gathering the material for movement, linking movements into phrases, and developing an orchestration style. For analytical purposes, we introduce these phases sequentially. Although presented here separately for clarity, these phases are overlapping and often undistinguishable in practice, as orchestration of care is a dynamic, never-ending process. Findings are illustrated in Figure 1 below in which dots represent materials that families gather for movement, lines represent movement, a group of lines form a ribbon, representing

sequences of movements, and the trajectories of the ribbons represent orchestration styles.

Figure 1. The orchestration of care as dance



Legend:
- Dots represent materials for movement
- A line represents movement
- A ribbon represents a sequence of movements (phrase)
- The trajectory of a ribbon represents an orchestration style

.[1]

[1] Considering it is difficult to represent movement in a two-dimensional figure, we invite readers to think of dance moves, as in the video in this link:

https://youtu.be/nfWlot6h_JM .

Gathering material for movement

Movements are patterns of sensing and responding (Lamothe, 2015). Movement is creating, becoming, relating. There is no dance without movement. For movement to happen, the dancer must gather materials such as inspiration, emotions, and energy. In orchestrating care, the family too gathers such materials to make movements. For instance, parents engaged in emotional labour (Hochschild, 1983; Wharton 2009) even before treatment began as they explained the circumstances of the illness to their children and the implications it had for their future, as they provided comfort and reassurance, even though they themselves felt the need for support. These parents' emotional work is instinctive, immediate, and illustrative of the empathic connection that exists between parents and children; this work drives movement as it includes the suffering of the children and other family members.

In *Why We Dance: A Philosophy of Bodily Becoming,* philosopher and dancer Lamothe (2015) illustrates this empathic connection as bodies that coincide and connect. Lamothe (2015) describes her baby's first smiles and her bodily reactions to it: 'Leif smiles. I smile back. He smiles more. I do too and add a squeeze. He giggles in response, and I am flooded with love. Leif's smile is an invitation to dance. I accept' (p. 136). As in this account of empathy through emotions, the feelings experienced during the initial stages of a CHC diagnosis also move parents to empathize.

> The hardest part is when you see the child suffer. The pain, the sorrow, the grief […] Well, and they feel bad too, diabetes also makes them feel weird. [At first] they don't know how to explain it or [how to] describe how they feel, [but] they feel weird and can't say anything very concrete. [...] The condition for discharge was that we had to be on point with the treatment. Therefore, we had to learn to control, learn to inject insulin. And that was an overwhelming process at the beginning, it was all like, it was very little time to learn all that, it was a lot of

> information. […] you feel that you will not be able to do it because you think it will hurt. The needle is very small, [and] if you position it well they don't even feel it. But then of course it will suddenly hurt and, and you don't know why […]. When you start at the hospital you must use a syringe […] Which is more traumatic [than the pen], just looking at it, for the child it is more traumatic. (Joaquín).

Joaquin and other participants hold vivid memories of the empathic and embodied connection between themselves and their children during the initial stages of the treatment. They will draw on this connection as material to learn about and respond to their children's bodies and their own: the tension before the pain from the needle, the long waits at the hospital, the anxiety about the unknown, the lost sleep. In the hospital, parents gather material about the medical procedures they will be required to master; these are the movements they will repeat daily. And as Joaquin notes, these movements will reverberate (pain, trauma, crying) in their children, creating other movements that parents will also empathize with, leading to the continuous chain of sensing and responding that is the dance between them.

Although these first medical interventions keep the family moving in the medical arena, they also demand a pause in the emerging caregiver's normal life routine. Participants recalled cancelling social events, returning home earlier from work, taking days off and 'stopping everything else.' In doing so, they are gathering energy, time, and focus as materials for movement. Marina explains:

> I was getting ready to go to a wedding, and they called me from the clinic: 'Sit down; take a pencil, paper. Your child has 836 glycemia [...].' I already knew that 800 was irregular. So, I said, 'Okay, forget the wedding.' And from there, I called the doctor and the lab had already called him: 'I am waiting for you here at the clinic'. And from there a whole lot of change came that I couldn't understand […]. The weight of the world dropped down on me because I knew that I was the one who was going to carry the baton. (Marina)

Those initial, highly disruptive moments forced Marina to refocus, and to look at how she spent her energy and time. As she was confronted with the challenge of having a child diagnosed with T1D, she felt 'the weight of the world' upon her. Although difficult, this realization anchored Marina. She was now highly aware that the lives of those in the family would never be the same, and that adjustments and sacrifices would be unavoidable.

Anchoring is an important aspect in dance. Muller and Ladewig (2013) note how in Argentine tango, for instance, 'the idea of stability comes from a good connection to the ground. This good connection to the ground ensures balance and a smooth walking and turning. The centre and the legs receive their stability by 'thinking into the ground' (Muller & Ladewig, 2013, p. 306). In the orchestration of care, anchoring is a result of the realization that someone will need to orchestrate care, and that orchestrating care will require time, energy, and focus. Julieta, a nurse specializing in diabetes, describes how the families she assists usually live through the initial anchoring phase, immediately after the diagnosis:

> Parents, grandparents, and siblings also [get involved]. That is, when they arrive here, I say: This is a mourning process, and each person mourns in a different way. […] Everyone lives it in a different way. Then, we go and show them how: It is normal that you are feeling this. Go ahead, we accompany you, we support you, we are with you. Let's do it this way, what do you think? And we try to have a super close dialogue with the family so that they really feel [...] that diabetes is not a limitation and that you can do everything you ever dreamed of with your child. (Julieta)

Nevertheless, anchoring does not always happen immediately as with Marina, or through institutional support as with families Julieta connects to. Each family finds its own ground, its own basis for movement, through a different process, at its own time. Elena reflects on how accelerating that process unbalanced her family:

> I would say that for me it has always been all as if it is super normal. [...] I said: 'Magdalena, you're going to be like your uncle Daniel' [who also suffers from diabetes] and it's over, we keep going forward. I went a little to the other extreme in the sense of trying to normalize it a lot, and a year after diabetes started to affect her, I felt that she did not have any space to be with her sorrow […] we ended up going to the psychologist, the YDFC, and everything. (Elena)

As she sensed that her daughter was not able to gather the emotions needed to move forward in the search for balance, Elena connected to others who could help her continue to move: the psychologist, the YDFC. These partners in the dance also bring in materials for movement—they too empathize and support patients and family members in connecting to their own emotions and finding the energy necessary to continue moving.

Finally, the family itself is a rich source of materials for movement. Carolina, for example, draws on her family's historical tenacity to gather energy and emotional materials that will prevent her from being 'stopped,' and that will 'push' her daughter into daily movement:

> Fernanda knows that she has to have a normal life like anyone else. […] The Alonsos [my mom's family], we have a saying: the Alonsos do not give up ... And so, we have to face different challenges, we repeat this to the girls every day: The Alonsos do not give up. […] Fernanda grew up in a super positive environment, where you are not going to be stopped and there are also people behind you who are going to push you. (Carolina)

The experience of helping other families who are initiating the orchestration of care for a CHC patient is further evidenced in the documentary 'Safely in the Rainbow' (Wendy Mangeant, Safely in the Rainbow, documentary). The Mangeant family documents the life of their child from his diagnosis of diabetes at 2 years of age until his late teens. It explains how they designed a visual for diabetes care that had worked for

the family: a rainbow that represents the spectrum of optimal glycaemia levels (70-170 mg/dl) to promote healthy living. Its colourful form offers a fun and easy way to understand the daily management of diabetes for all ages (Figure 2). The documentary shows how, when life is perceived as stable and controlled, some families can invest time in helping other families navigate the condition by adopting a more inspirational orchestration style.

Figure 2. Screenshot from ‘Safely in the Rainbow’ documentary.

Wendy Mangeant’s Safely in the Rainbow documentary recounts how family helped her find materials to continue moving when she spent 7 days at the hospital with her son Pâris, who was diagnosed with T1D at age 2:

> In those first few days the outside world ceased existing for me. Learning to give injections was painful for all of us. It was overwhelming because there was so much to learn: weighing food, counting rations, calculating insulin, doing tests to measure his blood sugar, learning when he needed extra insulin to correct a high number and when his numbers were too low and he needed sugar and food fast […] sometimes all we could do was make it from one meal to the next. When Pâris [T1D son] was sleeping, I didn’t feel very brave, but then [my husband] and [daughters] would visit, and he’d remind me I wasn’t alone. We were a whole family and that made a big difference (Wendy Mangeant, Safely in the Rainbow, documentary).

In addition to showing how family can be a source of materials for movement, Wendy’s account highlights that caring for a child with T1D requires certain movements to be repeated regularly (e.g., weighing food, calculating insulin, doing blood tests) and others that are only required as responses to what happens to the child

or the family (e.g., hypoglycaemia, which requires fast reaction). Orchestrating care requires work, as orchestrators need to link different movements into sequences (i.e. phrases), as we discuss in the next section.

Linking movements into phrases

In dance, a phrase is 'a series of movements bound together by a physical impulse or line of energy and having a discernible beginning and end' (Encyclopaedia Britannica, 2020, np). Emerging orchestrators often learn the basic movements of healthcare at the hospital (prick fingers for blood, measure glucose, calculate insulin dose, inject). These initial movements form the basic phrases for the orchestration of care in the context of CHCs. Yet, following the logic of care (Mol, 2008), we found that each family creates movements and phrases on their own as they return home and begin sensing and responding to new demands. They reconcile the new requirements of caring for the T1D child with the routines and phrases that were already part of family life. The quote below, from a booklet distributed to parents by the YDFC, illustrates how challenging it is to create and incorporate new phrases into an ongoing dance:

> When you go shopping, you no longer just look at the price, you have to also read the ingredients list for each food item. You are also beginning to realize the numerous things you need to do and purchase each month to take care of your child, such as a set of supplies, including test strips, along with insulin and syringes. During these times, it is understandable if you feel overwhelmed at all the strange tasks you need to do, but, little by little, these will become routine and everyday activities (Fantuzzi & López, 2015).

As the quote makes clear, incorporating new movements, such as more carefully selecting food for the family, adds complexity to family routines ('no longer just look at the price') and takes time ('little by little'). Once phrases are ideated and habituated, their movements can be considered anchoring—they become routinized and provide

stability for the family; they form the predictable part of the complex dance that caregivers enact over time.

Ana María describes her caregiving routine with daughter Jacinta, which illustrates how she developed long, repetitive, and paced phrases by sensing and responding to movements in the caregiving routine:

> Jacinta controls [her condition], and this year, [now] that she has lunch every day at school, she calls me for the controls: when she arrives at school [before] classes start, 2 hours later, at the first recess she calls me, before lunch she calls me. The second recess, 2 hours later, she calls me. Then, I have all [the measurements] controlled. (Ana María)

Although repetition and routinization help orchestrators deal with the instability of caring for a CHC, some issues remain. For instance, participants reflect on the challenge of reconciling phrases that may not be harmonious into a unified dance. Elena's morning routine with Magdalena and her other child is one such example:

> One tries to avoid much interference in family routines, but it is a big change. […] In the morning, waking up for us is—I wake up my two children and bring them to my bedroom to get them dressed. One goes to kindergarten and the other one to first grade at school. And I wake them up both with kisses, obviously, but with her [daughter with T1D] it is immediately 'Magdalena, you have to prick your finger.' So, this is different from saying 'Have your breakfast' which is what I say to the other kid. To her it is 'Magdalena, prick your finger.' (Elena)

As the orchestrator of care in her family, Elena has to reconcile the practices of diabetes care with the other practices of care in regular family life. Having a member with T1D produces imbalances in the family ('have your breakfast vs. 'prick your finger') and implies that other activities requiring time, energy, and emotions may be neglected.

Further, the unstable nature of CHCs introduces additional unplanned disruptions that require caregivers to move quickly. They need to urgently improvise the linking of movements into phrases to overcome life-threatening circumstances. Carolina describes the nervous and dramatic phrases of her overnight caregiving dance, which requires very forceful movements and large inputs of energy:

> Getting up at night 2 or 3 times because she is high, because she is low, because the whistle blows in my ear. Piiiii! She's low. You have to run, give her juice. And then you gave her too much juice and Piiiii! She's high and you have to inject. (Carolina)

As the vignette suggests, the constant movement and the intensive repetition of complex phrases is as exhausting for the caregiver, as it is for the patient. Carolina ponders about how the combination of such intensive phrases with other family and life routines impacts their search for balance:

> I get tired, I'm run down; I'm exhausted. Does it pain me? Yes […] But if you think about [my daughter], when she wakes up, she has not slept through the night. And she has to go to school and endure the 8 hours sitting on a bench. So, the fact that I have to wash clothes, drop the others at school and go to the office for 4 hours is nothing; my life is easy. (Carolina).

Similarly, Ana María reflects about how worn out she is because of the constantly repeating phrases and the required alertness to respond to multiple stimuli:

> It is enslaving […] ... I know that I arrive at work and that, in 15 minutes, I have to call Jacinta. […] At night, in the beginning, it was very enslaving because we had to wake up at 3 in the morning to control her. ... For about 2 months, we were like this […]. Currently, at night, it is still enslaving in the sense that [we have to say] Jacinta, inject. Jacinta, inject insulin… Inject insulin…If we go to a birthday party, I cannot spend time calmly talking with another mom. I'm observing what Jacinta is doing […] And if I see that it is tempting, [I say] 'Jacinta, let's get you some food [and then we calculate and inject insulin].' So ... It's enslaving. What if they

> offer ice cream, too? Ok, take it. But let's inject insulin. So, it is enslaving; that change is strong in that you are never enjoying a relaxed activity, but you are always alert to where [your daughter] is. (Ana María)

Ana María's testimony echoes Lamothe's (2015) description of skiing, where cultivating a state of alertness is fundamental:

> In order to get around the gates on a slalom[2] run, you can't repeat movements learned from a coach, teammate, or book. You must be alert yourself, attuned to the nuances of the snow, light, and temperature, keyed to the pounding of your heart, the throbbing of your thighs, and the depth of your breathing. You have to create patterns of sensation and response in multiple split-second decisions that align what you can do with what is required so you can make it down the mountain in the most expedient way. You have to *dance*.

Orchestrators of care must cultivate daily alertness and intense engagement for learning the phrases and integrating them at the appropriate moment. The relevance of this integration is critical, as disharmonized movements or the loss of alertness entails life threatening risks, as Wendy's account of caring for her son Pâris, diagnosed with T1D at age 2, illustrates:

> Just a few weeks out of the hospital, when I was still learning how to manage diabetes, I accidentally gave Pâris an overdose of insulin. His blood sugar level at bedtime had been very high, over 300, so I had given him an extra injection. Yet when I measured his blood sugar one hour later it hadn't gone down, so I gave him another injection of insulin. It was the middle of the night and I knew I had to do an additional test in half an hour to make sure he was going down but not dropping too fast, but I fell asleep and didn't hear my alarm go off. Only 15 minutes later I woke up on my own and in a panic raced into Pâris 's room, where he was sound asleep. I did a test and the monitor said low, which meant his blood sugar was so

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[2] An alpine skiing and snowboarding discipline that requires skiing around obstacles

> low the monitor couldn't even find enough sugar to measure. (Wendy Mangeant, Safely in the Rainbow, documentary)

Wendy's emotional account highlights the insufficiency of careful management in caregiving because of its unpredictable nature under unplanned life disruptions. While learning the phrases in order to perform together, just as dance partners do, families must also sense and respond to every movement. Wendy's lack of sleep and energy interfered with her ability to sense and respond to her son's need for care. She was, in that particular instance, out of balance and too tired to keep her movements as precise as needed for that dance. At other times, orchestrators opt for synchronizing their movements to those of others; one caregiver's lack of movement could lead to faux steps, jeopardizing the entire performance:

> When we got there [a remote location for vacations] we followed our routine of waking up all together, going to the beach all together, going to bed at the same time. We were all diabetic. (Soraya, Diabetes Control Magazine, n. 28, p. 22).

Although led by an orchestrator who guides the dance, the orchestration of care is a collective effort. Each family member has a particular way of gathering materials, of moving, and of linking movements. As a collective, each family develops an orchestration style, with styles as varied as dance genres, or even dance troupes' interpretations within genres. In the next section, we explain the orchestration style.

Developing an orchestration style

Due to the health risks that a CHC represents for their children, our participants are presented with extreme cases of the common parental challenge of dividing tasks between family members, outsourcing other tasks, and letting their children dance to the rhythm of their choosing. Letting go and trusting is itself a dance phrase to be created,

learned, and linked to other phrases.

Parents live in constant tension between centralizing and delegating duties, particularly during the initial phase of living with the condition. Some parents experience difficulties in trusting others with care duties, whether external providers or even the patients themselves. T1D patient Cristián reflects:

> When I had the first onset, I did not have diabetes; my mom did. She was the one who measured [my blood sugar] and the one who injected [insulin into] me. She was the one who took charge of my duties. (Cristián)

Similarly, Montserrat's mother says she 'became [her daughter's] pancreas.' She explains:

> Being in charge is as if one were diabetic. One has to act with the same discipline and responsibility, given that it is so difficult to gauge these episodes [of hypo and hyperglycaemia] when one has not lived through them. (Unnamed Mother, Diabetes Control Magazine, n. 28, p. 27)

When care orchestrators choose to retain control, other caregivers and patients themselves find it difficult to know when to move and when to incorporate their movements into the dance choreographed by the lead orchestrator. A father recounts his wife's orchestration of care for daughter Paula, diagnosed with T1D at age 4:

> She would cook everything separately for Paula. She did not let [the child] go to school anymore. After a while, she gave in and Paula went to class, but [the mom] stayed there all day. She did not go anywhere because she was in charge of injecting her and thought that everyone else was intruding. She slept with [daughter] from Sunday to Thursday to take care of her at night, and the rest of the days, I stayed in the room, so she could rest. (Galindo, Diabetes Control magazine, n. 40, p. 7).

Choreographing the orchestration of care was difficult for Paula's mother. She explains it as 'her psychosis' and remembers 'throwing the insulin against the wall'

because she couldn't get her daughter's glucose levels to stabilize and 'didn't understand why I injected this nasty thing in her.' At that point, the mom reflects, the dance she was orchestrating 'was a tragedy' (Lilian, Diabetes Control magazine, n. 40, p. 7). It took Lilian four years after her daughter's diagnosis to dance more fluidly, and to allow others to join the orchestration of care. As the pursuit of balance extends to other life domains, such as work and rest, family members adjust and sacrifice to compensate for the energy, time, and attention that one or more family members dedicates to dealing with an unplanned disruption. Take Diego's account of the transformation faced by his family:

> My wife stopped working. Because we had to control [our daughter's diabetes], we had to inject her with insulin. Then, because of the insulin, my wife stopped working. She took [our daughter] to school, went home, went to school again at lunchtime, controlled her glucose with insulin, went to look for her, sometimes stayed at school. In other words, it was the only way we could stay calm. I mean, I worked, and I was calm because my wife was taking care of [our daughter], but my wife had to stop working. And this leads to a whole story […]. When we lived on two salaries, the debts we had could have been paid between the two of us. But [dealing with the CHC] generated an economic setback. We got into debt, a whole deal, which was simply because we could not continue paying what we had committed to […]. And we made do for a long time like this. But at that time, [my wife not working] was what gave us peace of mind. (Diego)

The constant dance of care for a T1D patient, which requires insulin to be administered frequently and in the right dosage, combined with the profound consequences of making mistakes creates a context in which other family dynamics become relatively less important. In Diego's case, the family sacrificed by having the mother focus full time on caring for the daughter. This created an imbalance in the family's finances, but it was perceived as less threatening than not being able to orchestrate close care. In this case, for the dance of care to keep going, something else

had to stop. This trade-off is painful, requires sacrifice, and prompts family members to gather materials for movement from one another. For example, Diego notes how his wife giving up her job helped him to keep calm and continue facing his professional duties. He knows being in debt is not ideal, but this orchestration style made their dance possible.

External materials such as technology are also instrumental in the developing of orchestration styles by families. For instance, automatic devices for the administration of insulin (e.g., iPort, 'pumps') now support the care of many children around the world. However, these devices are not yet fully funded by medical insurance nor public health systems for all families. A participant, Bruno, notes: '12,000 people are diagnosed with T1D in Chile every year, and only 800 have the pump.' The automatic system for measuring glucose and administering insulin changes the orchestration style as it allows the family to outsource many of the healthcare phrases that orchestrators must enact daily: 'During the day [my daughter] now takes care of [her T1D]. Of course, we remind her that she has a little machine that keeps telling us her glycaemic levels all day long.' (Carolina)

Families who do not have access to such market-ready resources struggle to overcome instability in the orchestration of care, and often creatively engage others in developing an orchestration style. Marina, for example, raised money through crowdfunding for an insulin pump. But this did not solve her long-term financial needs. She now orchestrates to raise money on a monthly basis:

> People told me to get him the pump, but it costs around [250 dollars a month], and I don't have that. Suddenly, my friends told me, 'And what are friends for?' […] I [told them] I can't tell my son I will give him this life changing option, and four months later tell him, 'You know what, my five friends are no longer there for me.' I need him to have this until he is 20. This has been very challenging for me. Some

> of them forget to make the deposit, I need to remind them, and then I thank them. I learned how to ask for money, but it is hard for me (Marina).

Marina's case shows that orchestration requires constant movement, not only to enact practices of care but also to gather scarce materials (financial resources, energy, discipline, new skills), to execute new movements, and to connect them into replicable phrases. The difference between families in their access to materials is reflected in different orchestration styles, and these are always in constant flow and adjustment, evolving with time. For instance, when the child with T1D grows, when knowledge is gathered, or when bodies stabilize in response to medical treatment, the dance changes:

> Gradually as he grew, so did his abilities and with new abilities came new freedom. A freedom to take more responsibility for his own safety and keep his balance. Gone was the little boy wholly dependent upon his parents for his moment-to-moment well-being. With every passing year he was learning to listen to the signals of his body. Pâris was on the road to independence. (Wendy, Safely in the Rainbow)

For Wendy and her family, many years went by before Pâris could dance (almost) solo. Participants note how the carefully created balance once again slips into imbalance when the patient assumes control and responsibility for self-care. Parents experience tension in their relationships with children as their presence is less solicited. The orchestrator needs to manage tensions and find the right timing to be more detached. As such, nurturing the child towards autonomy represents a major shift in a family's orchestration style.

During these transformations, participants often felt they were being evaluated and judged on their efforts by their social network and service providers, and were prompted by others to let go of the constant dance. This is often a difficult realization,

as Susana recalls from attending family therapy when her T1D son was entering adolescence:

> [The psychologist said:] Draw yourselves. You have to be fish; you have to be maritime. Alvaro [the diabetic son] put himself in a fishbowl […] My ex-husband was a killer whale like that but black, black and badly painted, but he was leaving, escaping, escaping. And I was in the middle of everything […] I was like a dolphin, a very good thing, very neutral. And I said: Oh! poor Alvaro, he drew himself in a fishbowl, he must feel trapped, How terrible! Then the psychologist told me: No, that's you, the fishbowl is you. Overprotection, you don't let him breathe […]. You don't let him breathe. Let him breathe, let him have the ups, the downs […] I didn't like his analysis, because I didn't think I was doing a bad job. But they told me to let him go, to let him have lows, to let him have a scare, that he had to be independent. (Susana)

Used to sensing and responding to changes in her son's physical condition and emotions as a child, Susana faced unexpected tensions when he reached adolescence. At this stage, she felt out of balance again and felt that her dance had lost its significance. Like others, Susana revisited her involvement in the orchestration of care and took a step back to support her son with materials for his own movements. She now claimed that all she wanted was for him

> To be happy, if he wants to [measure glucose levels] he should do it, if he doesn't, he shouldn't. I [care] because I love him, I adore him. But he must do whatever he wants, I know he will, and be happy.

Whereas Susana reached this transformation through family therapy, other families send their children to YDFC's summer camp to assist them in finding their own orchestration style. At the camp, phones are forbidden and communication with the family is restricted. The teens learn from each other and from specialized tutors about how to better care for themselves. At the same time, parents learn how to incorporate

greater pauses into their own dances and experiment with more detached orchestration styles.

This gradual transfer of agency from parent to child liberates materials for use in new collaborative projects. Extra energy and time, for instance, can be used to help other families and children in similar situations, which may prove to be a rewarding experience. The capacity to liberate materials, like time and energy, and to create collaborative projects outside the family nucleus, generates aerial movements, i.e., those that enhance connections with others and instil in the participants love, kindness, and hope. In other words, as their style of orchestration matures, orchestrators are ready to share and support others in the same process, and thus an aerial interpretation of the dance takes place. For example, a participant mentioned joining a Facebook group which seeks to increase the speed of innovation in digital health. Started at Stanford University in 2013, this patient-led biotech initiative sought family balance as well as improvements for patients with this CHC. In this group, several parents with technological business affiliations, and who call themselves D-parents ('diabetes parents'), are willing to contribute to the development of a new open-innovation ecosystem for medical technology, which includes active patient participation beneficial for all families.

Discussion

The metaphor of dance best captures the orchestration of care that goes on in families dealing with members suffering a chronic health condition (CHC). The use of this metaphor brings a fresh perspective to understanding care in families. We find that it is through movement, as in dance, that family members, when confronted with unplanned disruptions, discover alternatives and act. These findings extend previous research on family care in consumer research, which predominantly uses the managerial perspective. This managerial perspective falls short in capturing the experience of caregiving when it is impossible for consumers to plan, habituate, and/or outsource practices of care. But when these two approaches are combined in an extended perspective, we are able to capture more dimensions of family care and recognize the full range of care practices that consumers engage in to find balance within the family unit. In the next section, we elaborate on this extended perspective.

An extended perspective on family care

Caregivers have traditionally been seen as recruiters, trainers, motivators, and managers of actors in the care system who support the habituation of new care practices (Epp & Velagaleti, 2014; Thomas & Epp, 2019). This managerial view focuses on how caregivers and their families can experience a level of control over the challenges they face and experience a feeling of internal organization and coordination even when agency is limited (Huff & Cotte, 2013).

Managing the family and the practices of care often equips families to confront life's challenges and to make an appropriate and reasonable use of marketplace resources (Pavia & Mason, 2004, Mason & Pavia 2006). For instance, the Elderly Consumption Ensemble (ECE), put forward by Barnhart and Peñaloza (2012), is a

group of family members and service providers who assist the elderly whenever they are unable to consume independently by dividing consumption duties among group members. Collaboration between ensemble members is presented through the framework of division of labour, thus translating these unplanned and disruptive life circumstances for the universe of consumption. This division of consumption responsibilities responds well to a managerial perspective of care, which provides interpretations about managerial procedures such as decision-making, negotiation, or outsourcing. Yet, it does not account for the hardest part of caregiving: 'the delicate "dance" of trying to help [elderly relatives] while still respecting their own right to make choices for themselves' (Kernisan, 2014, np).

When used with the managerial perspective, an extended perspective using the dance metaphor offers a more comprehensive account of the orchestration of care. It considers the instability inherent to unplanned life disruptions as well as the alertness and sense of urgency that animates families facing immediate and/or consistent life threats. In such contexts, there are no ready-made solutions or by-the-book protocols relevant to all families. Families have to create their own routines, their own dances, which can only start where management stops.

While the managerial perspective helps explain how families organize, negotiate, and optimize the resources available to them through a series of outsourcing and insourcing activities, viewing orchestration of care as a dance enriches the perspective of the assemblage work that parents do when outsourcing parenthood (Epp & Velagaleti, 2014). For instance, while current research with a managerial focus discusses how the market allows parents with economic means to *choose* to outsource care-related tasks (Epp & Velagaleti, 2014), and analyses how these families may need to work to minimize tensions related to this *choice*, our extended view of orchestration

of care illustrates how, under disruptive circumstances, families often have no choice but to suddenly adopt a set of new and complex care-related practices that are essential to their child's survival, whether they have the economic means to outsource or not, and whether the market offers them solutions or they must create their own. Accordingly, we discuss how families under disruptive circumstances, rather than choosing a solution, managing its implementation and avoiding or resolving tensions (as portrayed in research with a managerial view), must embrace tensions, as these families are often confronted with the fact that there is no one-fits-all solution to their care needs. We show how families fluidly and creatively navigate complex care requirements in a never-ending dance.

Orchestration as dance also goes beyond the trial-and-error approach used in ECEs (Barnhart & Peñaloza, 2013) and the division of labour in outsourcing and insourcing (Epp & Velagaleti, 2014). Under disruptive conditions, families are tested to the extreme. We show how, often, there are no opportunities to choreograph or rehearse this dance of care. In those situations, negotiating roles and distributing tasks are insufficient to care properly. Given the impromptu nature of care demands related to a CHC, orchestrators always need to be fit and warmed up. They must be able to trust absolutely in their dance partners yet be prepared to play all roles should any of them fail. Finally, the dance, learned by multiple actors on the go, is often awkward rather than beautiful, but it must be rapidly perfected and assimilated, and it must change styles to accommodate any changes. Orchestration exhausts the dancers, but—as if wearing cursed red shoes in the Andersen (1845 [2014]) tale—they cannot stop dancing, for the life of the ones they are caring for, as well as their own life's balance, depends on this.

In sum, this study extends the managerial perspective of family care by theorizing about the movements that constitute the orchestration of care. The dance metaphor goes beyond the limiting and rational approach to care work as a sum of decision-making processes; it makes bodies visible in the movements that animate practices of care. As Nowakowski (2016, p.901) highlights, orchestrating care involves 'the constant quest for the smallest victories.' The dance metaphor lays bare families' clumsy attempts at creating life balance and challenges the ideals of ready-made, market-based solutions for family care. As orchestration involves constant movement-in-the-making, families only ever achieve an unstable balance and imperfect synchronization. Therefore, they need to constantly sense their way to find creative ways of responding to evolving life challenges. This flux is best captured by the metaphor of dance. Hence this extended view of orchestration of care, combining the managerial and dance perspectives, provides a more comprehensive understanding of how the family interprets the context, is affected by it, and then finds its own way of healing.

Implications for future research

Our research adds to prior calls for the dominant view centred on the market and on the consumption experience to be contested (e.g., Fitchett, Patsiaouras & Davies, 2014): we agree that research spaces are needed "where the logic of consumption can be questioned in more critical terms, perhaps examining contexts where consumption either does not and arguably should not, be the primary unit of analysis" (Fitchett, Patsiaouras & Davies, 2014, p. 503). The dance metaphor focuses our analysis on the family well-being objective, acknowledging that the marketplace and the consumption activities are part, but not the core of family care.

This study also opens avenues for future research on systemic aspects of caring. One of these aspects is, for instance, the care inequalities among young patients because of their family's lack of resources. The lack of financial and social resources is an important barrier for families as they gather materials for moving into phrases and develop an orchestration style. When their creative capacities are diminished, families may suffer in their capacity to sense their options and possibilities.

Due to the multiplicity of treatment options, clinical trials, support organizations at the national and international level, different levels of institutional support such as at schools, and the characteristics of each family, some families end up receiving more support and better treatment, while others remain more vulnerable. We argue that these disparities in the provision of care have a dual component. One component is connected to the managerial aspect of care and targets a family's capacity to access external resources; the other component is connected to the dance metaphor and refers to a family's inability to gather materials for movement, to link movements into phrases that can be incorporated into the existing family routine, and to understand their own needs in terms of finding balance and developing a unique orchestration style for the family.

Our analysis shows how families can manifest an incredible capacity to orchestrate care and to collaborate with market and non-market actors in ways that have more potential than one market actor alone could have in addressing the needs of a CHC. In this sense, public organizations have a duty to consider and help develop the creative capacity of families, and that of leading orchestrators, to find and adapt market resources to their own care needs and orchestration styles.

Future work should consider also the gender inequalities that are exacerbated in orchestration work. Consumer research has shown how discourses such as intensive

mothering (Hays, 1996) and slow parenting set standards for being a 'good' parent. When a family's care needs become intensified by a CHC, additional cultural demands and control mechanisms exert pressure on families to enact care in set ways. Future research could, for instance, concentrate on understanding these forces, and on the patterns of movement that operate within gender discourses. Policymakers could use this research for several things: to make changes to the kind of resources that traditional caregivers can avail themselves of, and to help families and caregivers to interact and construct different, and more fairly distributed, roles and styles of care.

Another area of inquiry could be identity transformations for families. Researchers could look at how caregivers shift between the identities of caregiver, manager, and dancer. How would these multiple perspectives influence caregivers' and receivers' relations to other marketplace actors? What are the identity outcomes, for orchestrators of care, of approaching care from one or another perspective? These issues need further study, and we urge consumer researchers to dedicate attention to them.

Finally, although this research sits at the intersection of consumer research on family consumption and care, it also responds to calls to integrate scientific and artistic perspectives into marketing research (Tran, Goulding and Shiu, 2017, Hamilton and Hewer 2009). The capacity of art to jumpstart productive movement, for instance, has been highlighted in previous studies of product innovation by Tran et al. (2017). In the study, participants were exposed to technology-led innovation through music and were moved "from apathy, worry, and anxiety at the beginning of a challenge toward arousal and, ultimately, a flow experience that concerns 'conscious effort and the direction of psychic energy to produce a feeling of wellbeing' (Goulding, 2002: 270)" (Tran et al., 2017, p. 511). To further explore how art-like engagements can illuminate the way people innovate in order to enhance their caring for those in need, we echo calls for

“more empirical research on arts-based initiatives in developing theories of product design innovation (Shiu, 2017) and experience innovation” (Tran et al., 2017, p. 512).

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