Adaptation of the Day100 Talk Communication Intervention for Spanish-Speaking Families of Children with Cancer

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Abstract

The Day100 talk (Day100) bridges communication gaps between parents and clinicians early in pediatric cancer care through an interprofessional family conference facilitated by structured tools. We aimed to understand communication challenges and facilitators and to adapt Day100 for Spanish-speaking parents. We interviewed Spanish-speaking parents with limited English proficiency, Spanish-English medical interpreters, and clinicians to gather communication experiences and adapt Day100. Results showed that communication difficulties were precipitated by linguistic and cultural differences, nonvisual technologies, and limited spontaneous communication. Interpreters enhanced communication as linguistic and cultural brokers. Non-verbal cues also facilitated communication. Participants offered recommendations to adapt Day100 for future study.

Introduction

The initial months of childhood cancer care form a period of profound change and adjustment.[1,2] The Day100 Talk (Day100) is an intervention to bridge communication gaps between parents and clinicians through an interprofessional family conference facilitated by communication tools during the initial months of childhood cancer care. Day100 provides families of children with cancer an opportunity to regroup with their child's care team to address unanswered questions, concerns, and future goals.[3] In a recent study, Day100 exceeded pre-determined feasibility thresholds (60% parent intervention completion) and was highly acceptable to families and clinicians.[3] Sixteen million people in the United States speak primarily Spanish with limited English proficiency, forming the third largest linguistic population.[4] Parents with limited English proficiency may experience inferior communication.[5, 6] We aimed to adapt Day100 for use by Spanish-speaking families, clinicians, and medical interpreters by eliciting their perspectives and feedback.

Methods

This study was approved by the Institutional Review Board at Dana-Farber Cancer Institute. At this institution, approximately 5% of patients were Spanish-speaking. To triangulate data by exploring perceptions of different groups of participants,[7] qualitative interviews were conducted with a pilot cohort of Spanish-speaking parents, medical interpreters, and oncology clinicians. We aimed for a minimum of 3 participants from each group.[7] Interviews were conducted in person, via telephone, or via secure web conference from January 2019-February 2020. A bilingual interviewer trained in medical sociology conducted parent interviews.[8] Parents described communication experiences receiving childhood cancer care and reviewed/gave feedback on Spanish language Day100 materials, including the 3-part communication tool (preparatory family worksheet, conversation guide, and family summary sheet),[3] and parent surveys. Interpreters and clinicians discussed experiences communicating with Spanish-speaking parents and identified benefits and potential barriers to conducting Day100 with Spanish-speaking families.

A trained research coordinator determined eligibility through medical record abstraction. Eligible Spanish-speaking parents had children < 18 years old receiving care at a single pediatric cancer center (< 14 weeks of cancer-directed therapy and without relapse/progression upon approach). Permission to approach was obtained from each child’s primary oncologist (none declined). Participants provided informed consent. Five parents of children with solid malignancies who initiated treatment 2-12 weeks prior to approach enrolled. Four pediatric oncology clinicians and five medical interpreters enrolled. Participants were assigned study identifiers LEP (parents with limited-English proficiency), MI (medical interpreters), PS (psychosocial), NP (nurse practitioner), FE (oncology fellow), and MD (oncology attending), followed by randomly generated four-digit numbers. Interviews were audio-recorded, transcribed verbatim, de-identified, and analyzed using inductive coding, starting with open coding followed by iterative fitting to the data using the constant comparison method.[8,9]

Results

The following themes prevailed regarding communication experiences between Spanish-speaking families and clinicians: difficulties communicating concern and meaning, lack of spontaneous/unmediated communication, and communication enhancers. We additionally categorized utterances that provided feedback regarding intervention acceptability, feasibility, and recommended changes (Table 1 & S1).

Regarding difficulties communicating concern and meaning, parents expressed hesitancy to ask questions, particularly during telephone conversations. Interpreters and clinicians noticed this hesitancy in general and via telephone. Clinicians and parents lacked opportunities for spontaneous interactions unmediated by interpreters. While interpreters were present for formal interactions, they were not uniformly present throughout a child's day in clinic, such as while in the waiting room or throughout a prolonged infusion, rendering Spanish-speaking parents unable to learn from casual conversations around them. There was a shared sense that the pace of knowledge exchange was slowed by the lack of spontaneous communication and telephone-based communication. Clinicians struggled to convey meaning when explaining complex treatments and medical systems through an interpreter. Clinicians and interpreters highlighted difficulties in conveying meaning when a direct translation between words did not exist.

Parents also identified communication enhancers, like nonverbal cues during face-to-face encounters. Participants highlighted the interpreter role as promoting communication through expertise in both colloquial English and Spanish as well as medical terminology. Interpreters served as brokers of meaning, mediating between clinician and family to relay complex concepts to promote comprehension.

Overall, participants perceived Day100 as a resource to address unanswered questions and prompt conversation, and they found Day100 tools comprehensive, clear, and specific. Participants expressed willingness to participate in Day100 (S1).

Comments on intervention feasibility could be categorized as *enhancers* or *threats.* Participants expressed preferences for in-person or virtual face-to-face Day100s. Interpreters and clinicians highlighted potential benefits of having two clinicians (e.g. physician and social worker) present to serve as additional support.

For feasibility threats, work compression loomed large. Clinicians were concerned that Day100s conducted across two languages would be prohibitively lengthy. Clinicians also mentioned that it may be more difficult for interpreters to facilitate open-ended conversations rather than discussions that focused more on medical facts. Clinicians worried that the complexity of communication dynamics would intensify if multiple family members engaged in Day100.

To better tailor Day100, participants recommended including additional guidance on navigating the medical system, resources available, and querying specifically, "Are your needs being met?" Parents also recommended shortening surveys.

Finally, parents and interpreters were queried for feedback on word usage. Parents distinguished between the term *susto* (scared/fright) and *miedo* (fear) and expressed a preference for the use of the word *miedo*. One parent explained, "When they tell you 'Your daughter has cancer,' that's when fear appears. It's not fright but fear."

Discussion

Spanish-speaking parents, clinicians, and interpreters lacked opportunities to spontaneously communicate and experienced difficulties conveying concern and meaning. When Day100 was posed as an intervention to augment communication, participants regarded it favorably and offered recommendations to enhance Day100 delivery. Importantly, clinician comments about Day100 length and challenges with open-ended conversations suggest differential communication with families who have limited English proficiency. Given this, Day100 may provide a needed mechanism to regroup and address unanswered questions and concerns (Fig. 1), particularly when clinicians and parents are grounded in different cultural contexts. While Day100 does not address limitations in spontaneous communication, it may mitigate gaps created by constrained communication between parents and clinicians lacking a shared language.

This study has notable limitations, including conduct at a single center among a relatively modest sample of participants. Substantial variability exists in demographic composition, language fluency, and cultural contexts of clinicians and parents across institutions that provide childhood cancer care in North America.

Additional modifications may enhance Day100's value.[10] Planned modifications include queries about navigating the medical system along with existing psychosocial and supportive care resources. In a focus group study on the support needs of Latinx mothers facing childhood cancer, information on navigating the medical system emerged as a key theme.[11] Additionally, given parents' expression of anxiety regarding telephone communication and the potential positive impact of non-verbal cues made possible by face-to-face interactions, in-person or video-conference Day100s are more likely to be successful. Ideally, Day100 is an interprofessional intervention that incorporates a clinician with psychosocial expertise to serve as an additional layer of support. Lopez et al. highlighted the role of a social worker in culturally informed and supportive care for Spanish-speaking families.[11] Due to the nature of multi-lingual communication, Day100s conducted with medical interpreters may require more protected time. Time and work compression were limiting factors in the original Day100 study, and health systems should provide protected time to enable conversation depth.[3]

In conclusion, this study will inform further Day100 development, enabling intervention testing inclusive of Spanish-speaking parents with limited English proficiency.

Conflicts of Interest

We have no conflicts of interest to declare.

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Legend List

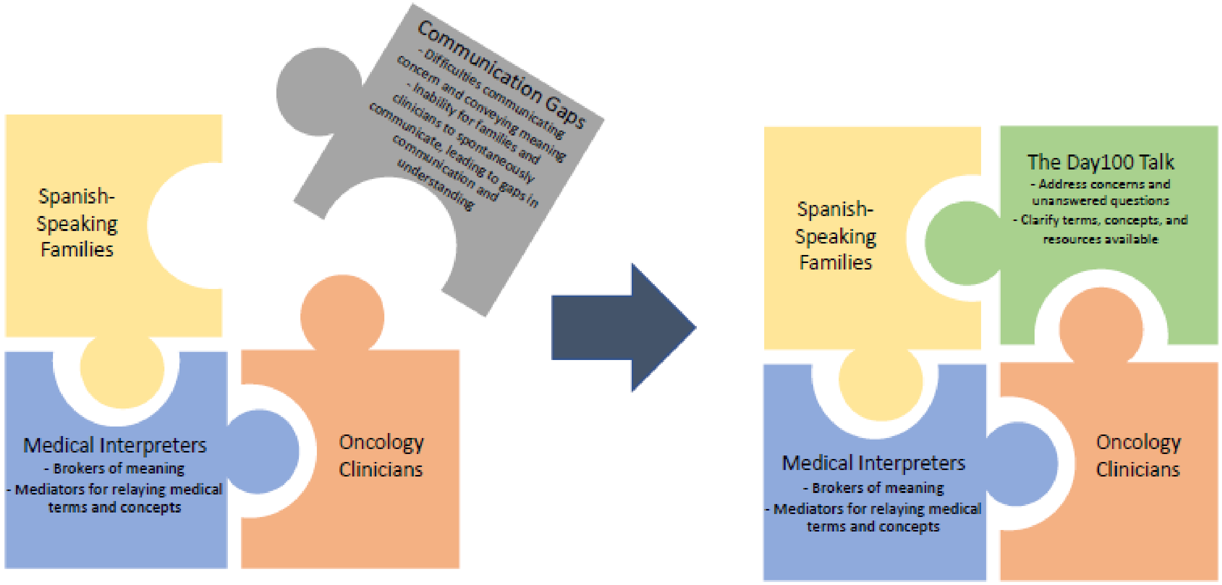

FIGURE 1 The Day100 Talk's role and potential impact within the parent, interpreter, and clinician dynamic. The interpreter's role is to serve as meaning broker and mediator, relaying complex terms and concepts between parents and clinicians. Difficulties communicating concern and conveying meaning still prevail, and, due to a paucity of spontaneous communication and connection between parents and clinicians, questions and concerns often go unaddressed. The Day100 Talk may ameliorate communication gaps by providing a scaffold for parents and their child's care team to clarify and address concerns and unanswered questions.

Table 1. Participant themes and illustrative quotes

Communication Difficulties: *Dynamics and settings that contribute to potential misunderstandings between Spanish-speaking families and clinicians.*	"What I find most difficult…about communication are the phone calls." - LEP7012
	"Sometimes they don't call us for infusion because it's a routine. So for example, last week, I went by, because they didn't call us and I said, did you see the nurse? And said yes, and did you understand what they told you? Not really. So sometimes because of convenience, they don't call us." - MI04
	"I think sometimes when we have maybe institutions, or terms that don't translate very well." - MI03
	"English-speaking families have the opportunity to process, comment on, ask questions about, kind of get – sort of soak in more information from the environment or from anyone... for a lot of our Spanish speaking families or other families that are not English speaking, that just takes a longer time because it's much more episodic." - PS4327

	"I think sometimes it's harder to convey the landscape of treatment options. But going through the nuances of that with an interpreter there, could sometimes be, I think maybe there's some confusion around that." - FE4286
Communication Enhancers: *Roles, settings, and dynamics that improve communication between Spanish-speaking families and clinicians.*	Communication is not only about language. There is much more. So if there is empathy and caring, there is going to be communication... If a doctor or a nurse, whoever, has a loving and empathic attitude, collaborating and understanding the patient, they try to understand the patient there is going to be a better communication." - LEP7012
	"When it comes to medical explanations, I do consider that we both need an interpreter because they are not only able to translate the language, but they are also very familiar with all the medical terminology." - LEP7012
	"Trying to explain why – our own medical culture is I think an important part of what helps people to kind of understand what we're doing and why we're doing it, even things that would seem not directly related to the care of a kid." - PS4327
Acceptability: *Themes highlighting the acceptability of the intervention.*	"The tools are perfect. It's a way of starting a conversation with somebody, it's a way of seeing the perspective of the person you're interviewing, it's good, all the tools are good. I'd feel good because I can ask all my questions, all my concerns in only one paper. And the moment I see the doctor and the medical team I'd be ready to ask the questions I have to ask." - LEP8822
	"This was very helpful. I think they are very precise, and the goals are very clear. It's very well written. I really like it and I think that would be very good to organize the people." - MI02
	"I think it's a great opportunity to kind of circle back with our families... there may have been question – things up front that we weren't aware of, either the family's understanding, their learning style, their lack of support, things that weren't addressed initially, that having this – and kind of as an acute issue – after acute issue comes up, they may not be addressed." - MD8375
Feasibility Enhancers: *Factors making the intervention more feasible.*	"I think an interpreter in person is much, much more desirable than using an over-the-phone interpreter." - NP9402
	"I think it's better with someone there, because you can express yourself....and they can understand better than if you write on a worksheet. Because sometimes you don't know how to write words, or how to say things in writing, but if they're there, they can understand much better." - LEP2529
	"Discussing in person." - LEP0640
	"And sometimes it's good to have a social worker. And when you said that it's gonna be there. For family meetings, I think it's really important that a social worker will be there." - MI02
Feasibility Threats: *Factors making the intervention less feasible.*	"When you have a lot of people, it depends on how many people are in the conversation, that can be a little bit challenging if everybody starts talking at the same time...so, that's always a little bit challenging to interpret." - MI01
	"To do this over the phone? Oh, that would be – I think that would be a little bit challenging." - MI01

	“I think the time factor would be a lot.” – FE4286
	“They [interpreters] wind up either summarizing in their own words or interrupting constantly, which, again, from a technical standpoint if you’re having a strictly medical discussion, it’s a good thing to do, right, but maybe for this discussion, that’s a little different.” - PS4327
Day100 Tools Comments: *Feedback and recommendations on the tools for improvement.*	It was a bit too long.” - LEP2704
	“You could add a paragraph where help is offered to the relatives. It could be a way of reminding them that if they need support there are social workers, psychologists, institutions that take care of that sort of things. Some sort of guidance for the person because sometimes when you talk about this type of disease you feel like the world is falling apart.” - LEP2704
	“Maybe it needs more of an introduction, more of an explanation of what the goal of these forms are...” - MI03
	“I think one of the concretes would be, do you feel comfortable calling with questions or navigating our system with interpreters that are provided? Or do you have concerns – really just kind of asking the question of, are we doing a good job with respect to our other language services and meeting the needs of our families. Are we providing materials in the correct language? Are we meeting your needs, from an educational language standpoint?”- MD8375
Day100 Translations Comments: *Feedback on interpretation of words and concepts.*	“When you say: “Tengo miedo,” it’s like stronger, it’s something deeper. It has more emphasis. I think “susto” is correct. A “susto” can be something temporary, like: “Ay, me asusté” but “miedo” is stronger.” - LEP2704
	“The meanings of those words are very different. Fear is to have fear of losing.” - LEP8822
	“And then, in terms of the words themselves, I think that – I think also, it need more. I think in Spanish, we tend to be a little more verbal, and this just sounded to me like there was just too much like English, in which everything is shorter.” - MI03