Understanding parents’ communication experiences in childhood cancer: a qualitative exploration and model for future research

Julia Baenziger1,2,3 • Kate Hetherington2,3 • Claire E. Wakefield2,3 • Lauren Carlson2,3 • Brittany C. McGill2,3 • Richard J. Cohn2,3 • Gisela Michel1 • Ursula M. Sansom-Daly2,3

Received: 17 July 2019 / Accepted: 23 December 2019 / Published online: 11 January 2020
© Springer-Verlag GmbH Germany, part of Springer Nature 2020

Abstract
Purpose Following their child’s cancer diagnosis, parents must rapidly familiarize themselves with cancer-specific information and the health-care setting. Theory-driven research is needed to understand and address parents’ difficulties when interacting with health-care professionals (HCPs). We examined parents’ health-care experiences during and after the child’s cancer treatment.

Methods We recruited parents of children/adolescents (aged < 18 years) who had recently completed cancer treatment with curative intent from eight Australian hospitals. We conducted in-depth interviews using the psychosocial adjustment to illness scale while recruiting for the “CASCADE” survivorship intervention. We used grounded theory to explore parents’ health-care experiences.

Results Fifty-two mothers and six fathers of survivors (mean age at diagnosis = 5.1 years, time since treatment = 1.9 years) participated. Parents’ experiences were characterized by (1) positive and negative interactions, (2) attitudes towards health care and HCPs, (3) trust and mistrust in the doctor-parent relationship, and (4) parents’ engagement in care. Parents built trust with HCPs, who seemed approachable and personable. Although parents’ experience was overall very positive, nearly half of parents reported negative interactions and mistrust. Parents rationalized negative experiences as caused by constraints in the health-care setting. Most parents felt support ended prematurely. We propose a new model accounting for these experiences and identifying potential underlying mechanisms.

Conclusions Depending on their degree of trust, parents followed recommendations more closely (high trust) or focused on being advocates for their child (low trust). Parents minimized the impact of negative HCP interactions through internal, rationalizing processes. Our findings demonstrate parents’ flexibility in acting as a dynamic buffer between HCP-interactions and their child.

Keywords Childhood cancer • Adolescent • Communication • Parents • Survivorship • Health-care professionals

Abbreviations

| n     | Number |
|------|--------|
| SD   | Standard deviation |
| TAFE | Technical and further education |
| BM   | Bone marrow |

SCT   Stem cell transplant
HCP   Health-care professionals

Introduction

Following their child’s cancer diagnosis, parents have to rapidly learn a considerable amount of cancer-specific information [1] and orient themselves within the clinical setting. Parents, the child, and the family system face prolonged treatment over several month or years [2, 3].

Parents have to collaborate with health-care professionals (HCPs) to make complex treatment-related decisions [1]. Conflicts may arise due to different views of parents and HCPs [4]. For example, there may be disagreements regarding how much information should be disclosed to the child about
the cancers’ severity [5]. Unsatisfying or negative interactions with the health-care team have been associated with decreased parental psychological functioning [6], and lack of trust in HCPs has been associated with poorer health outcomes [7].

Positive interactions between parents and HCPs remain important beyond the treatment phase and into survivorship. Parents may remain involved in their child’s long-term follow-up (LTFU) care into adulthood for personal (e.g. invested in their child’s health) and practical (e.g. transportation, information on medical history) reasons [8–10]. Survivors’ support network, especially parents, was seen to play an important role in survivors’ long-term care [11].

Little is known about parents’ experiences when interacting with the child’s health-care team particularly with regard to parents’ perspectives on their child’s past, ongoing and future health-care [4]. While previous studies described parents’ difficulties, parent-HCP communication processes have not been well-understood and thus “offered little contribution to theory development” (p.1258) [4].

Parents’ health-care and communication experiences have, to our knowledge, not yet been examined in the Australian context. A better understanding of the psychosocial aspects that shape the experience may help to identify what HCPs are doing that works well and reveal new ways to address parents’ difficulties and information needs [4, 12, 13].

We, therefore, explored parents’ reflections on their health-care experiences during their child’s past, ongoing, and future cancer care. Based on our findings and the current literature in the field of health-care-communication, we propose a model explaining the underlying processes in parents’ health-care experiences.

Methods

Population and procedure

Parents were recruited from eight Australian hospitals (03/2014–11/2018) to participate in a randomized controlled trial of an e-mental health intervention, called CASCADE (Cope Adapt Survive: life after CANcEr) [14]. CASCADE involved four 90-min online sessions facilitated by a psychologist in a group of three to five parents, delivered via videoconferencing.

Every parent who was eligible at time of recruitment (population-based) was approached and invited to participate. Parents were eligible if their child was aged < 18 years and had completed cancer treatment with curative intent. We sent a personalized study invitation letter along with consent form and opt-out card for study participation, which was voluntary and not reimbursed. Informed consent was obtained from all individual participants included in the study. Parents were excluded if they had insufficient English proficiency or if they reported extremely severe distress (e.g. current suicidal risk at assessment). In accordance with our ethics approval, our collaborating sites were not able to share any data on parents at their site who did not opt into the study. The opt-in rate was therefore only available for the Sydney Children’s Hospital: 30% of all approached parents completed the interviews.

Lead site ethics approval was obtained from the Sydney Children’s Hospital Network Human Research Ethics Committee (HNEHREC Reference No: 14/02/19/4.01, NSW HREC Reference No: HREC/14/HNE/44, as well as all other recruiting sites).

Measurements

We assessed parents’ socio-demographic characteristics and details about their child’s clinical characteristics using a paper-based self-report questionnaire before the interview. Experienced research officers (ER, KM, SE, LC, BM, see acknowledgements) interviewed parents by telephone using the psychosocial adjustment to illness scale (PAIS) [15]. PAIS is used to gain a better understanding of the psychological and social adjustment of patients to their illness (past 30 days); it is psychometrically sound and includes 46 questions covering seven life domains (health-care orientation, vocational environment, domestic environment, sexual relationships, extended family relationships, social environment, and psychological distress) [15]. In this study, we focussed on the life domain “health-care orientation” to assess parents’ adjustment in relation to their child’s health-care needs: Parents elaborated on experiences regarding health care (e.g. attitudes, perceptions, and expectations) and their understanding of health information (e.g. medical care, information from medical staff, prescribed treatments). Interviews were recorded and transcribed verbatim.

Analysis

We used grounded theory, an inductive, hypothesis-generating, approach within qualitative health psychology [16]. We performed line-by-line coding on parents’ narratives using NVivo 12 [17]. We first developed a contextualized understanding by reading all transcripts, before focussing on parents’ recollections regarding their interactions with HCPs. The study team with a background in psychology and/or education regularly discussed categories and themes. This iterative process was repeated until saturation was reached (50/58 transcripts). After establishing a firm coding tree, the secondary analyst (LC) independently coded 20% of the interviews. Average kappa was 0.80 for all nodes and sources (unweighted) representing excellent agreement [18]. Discrepancies were discussed and coding schemes adapted and applied to all transcripts. Descriptive statistics were calculated using Stata 15.0.
Framework

A co-constructivist perspective guided our analysis [19], where the individuals’ lived experience is seen as co-constructed through continuous interactions between the psychological, social, and physiological states.

Results

Participants

Of 76 parents who were approached and consented to participate, 61 completed the PAIS interview, of which 3 recordings were inaudible (excluded, Fig. 1). The final sample included 52 mothers and 6 fathers (range 22–55 years old; mean age 40.1 years; Table 1). Average time since their child’s treatment completion was 1.9 years (4 months–10.7 years). Most common types of diagnosis included solid tumours (34.5%) and leukaemia (32.3%). Parents were most often employed part-time (36.2%) and had mostly completed tertiary education (68.9%).

Model

Parents described (1) positive and negative interactions with HCPs (interaction, I+/I-), (2) their attitude towards expertise and treatments (attitude, A+/A-), (3) their trust and mistrust in the doctor-parent relationship (trust, T+/T-), and (4) their engagement in their child’s care (engagement, E; Table 2; Table 3). The paths also appeared to reciprocally influence one another (Fig. 2). For instance, new perceptions could evolve through interactions (IA), or parents’ initial health-care engagement could shape the way HCPs interact with the parent (EI).

We describe and illustrate how the categories and themes related to each other and thus became the basis for a new theory: the proposed model to help explain parents’ communication experiences in childhood cancer. Parents repeatedly articulated patterns when recounting their experiences (Fig. 2, black arrows indicating common pathways).

Interactions and attitudes

Parents’ interactions with HCPs and their attitude regarding expertise and treatment seemed to be the basis of developing trust in the relationship (quotes termed I+T+ and A+T+) or, on the other hand, prompted doubts and disappointments (I-T-/A-T-).

Positive interactions

Parents reported many positive experiences with HCPs. Parents described having received careful explanations of diagnosis and treatment:

“The amazing part was they included my son. He wasn’t just looked at as a patient, he was looked at as an individual,… they spoke to him first, and then they spoke to us, and we were so impressed. We, at that time, my partner and I said, you know, we trust these doctors. They not only have our best interests, they have his” [I + T+] (mother of a 15-year-old boy).

Parents also described having been actively involved in treatment and decisions:

“I feel like we were treated like we were a part of the team to get [survivor’s name] better… and that we were all working in order to get the best possible outcome for [him]” [I + T+] (mother of a 7-year-old boy).

Parents appreciated when HCPs were contactable and available to respond to their needs:

We describe and illustrate how the categories and themes related to each other and thus became the basis for a new theory: the proposed model to help explain parents’ communication experiences in childhood cancer. Parents repeatedly articulated patterns when recounting their experiences (Fig. 2, black arrows indicating common pathways).
“They were on top of it, they were very professional, there was not a day that you know, even if we called about that they would get back to us as soon as possible” [I + A+] (mother of a 16 year-old boy).

Negative interactions

Many parents recounted that throughout the cancer journey, they perceived having been misinformed, having to deal with medical mistakes or experiencing invalidating reactions from HCPs, such as HCPs seeming dismissive of parents’ opinions or appearing emotionally distant:

Table 1  Socio-demographic characteristics of parents and cancer-related information of childhood cancer survivors

| Parents’ characteristics, n = 58 | Survivors’ characteristics, n = 58 |
|----------------------------------|-----------------------------------|
| Mean            | SD       | Mean (SD) | Min, max |
| Age at study    |          | Age at diagnosis a | 5.08 (4.72) | 0, 15 |
|                  |          | Time since last treatment a | 1.94 (2.12) | 0.3, 11 |
| n            | %        | Categorical | n | % |
| Sex            |          | <2 years | 28 | 52.8 |
| Female         | 52       | 2–5 years | 5 | 9.4 |
| Male           | 6        | 5–10 years | 4 | 7.6 |
|                |          | >10 years | 1 | 1.9 |
| Marital status |          |          | |
| Yes            | 44       |          | |
| No             | 14       |          | |
| Migration background a |          | |
| None           | 41       |          | |
| Other countries | 10     |          | |
| Education      |          |          | |
| Year 12 or below | 7       | 12.1      | |
| TAFE certification or diploma, college | 11         | 19.0      | |
| University degree | 22     | 37.9      | |
| Postgraduate degree | 18     | 31.0      | |
| Employment status a |          | |
| Full time employed | 14       | 24.1      | |
| Part time      | 21       | 36.2      | |
| unemployed or student | 16      | 27.6      | |
| Number of siblings a |          | |
| 1              | 22       | 37.9      | |
| 2              | 16       | 27.6      | |
| >2             | 3        | 5.2       | |
| Diagnosis a |          |          | |
| Blood cancer   | 11       | 19.0      | |
| Solid tumours  | 27       | 46.6      | |
| Brain tumours  | 10       | 17.2      | |
| Langerhans cell histiocytosis | 1       | 1.7      | |
| Treatment a,b  |          |          | |
| Surgery only   | 2        | 3.5       | |
| Chemotherapy   | 31       | 53.5      | |
| Radiotherapy   | 12       | 20.7      | |
| BM or SCT      | 6        | 10.3      | |
| Previous relapse a |          | |
| Yes            | 9        | 15.5      | |
| No             | 39       | 67.2      | |

a Variables have missing values
b Blood cancers included leukaemia and lymphoma; solid tumours included sarcoma, neuroblastoma, kidney liver tumours

“The only time I felt like the care wasn’t good, you know was not taking into account that this is a child and it’s the family. It was more about ‘this is the way we do it and if you don’t do it this way then you’re wrong’” [I-A-] (mother of a 5-year-old boy).

Parents reported that they felt they lacked guidance during treatment and following treatment completion. They reported difficulties when treatment procedures were not clear, when HCPs were unavailable for questions, or when HCPs used medical jargon. A mother explained:

“There have been quite a lot of problems, lack of communication, in relation to appointments or information and I’ve...
Parents felt that support ended prematurely at the end of their child’s treatment: “I’ve really struggled to get help to identify people, who are people who will take her case on… that’s been a real issue for us” [I-Eproactive] (mother of a 15-year-old girl).

Parents were also unsure about recommendations regarding the early post-treatment period and into survivorship, and many did not recall receiving any concrete advice for the future: “I must say I was quite surprised during the process that little to no advice is given about, things you can do” [I-] (mother of a 7-year-old girl).

### Table 2

| Theme           | Subtheme                              | Path label |
|-----------------|---------------------------------------|------------|
| INTERACTIONS    | careful explanations                   | I+         |
|                 | participative                          | I+         |
|                 | contactable and responsive to needs    | I+         |
|                 | negative interactions                  | I-         |
|                 | lacking guidance                       | I-         |
| ATTITUDE        | great expertise and care               | A+         |
|                 | committed and dedicated HCPs           | A+         |
|                 | treatment uncertainty                  | A-         |
| TRUST           | trust in HCPs                          | T+         |
|                 | mistrust and disappointments           | T-         |
| ENGAGEMENT      | managing information needs             | Einfo      |
|                 | proactive                              | Eproactive |
|                 | follow-up is important                 | Efollow-up |
|                 | rationalising                          | Erationalising |

Abbreviations: HCP, health care professionals

Note: Coloured shading matches Fig. 2: positive experiences = green; negative experiences = orange; parent’s degree of trust (low-high) = light–dark blue; type of engagement in care: based on positive experiences = green, based on negative experiences = orange, variant by parents’ degree of trust = blue.

Parents perceived the care their child received and their health-care team’s medical expertise to be very good. A mother describes her child’s oncologist: “He is so knowledgeable and so experienced, all this came across. You knew, whatever his recommendation was that was the best. We had such a belief in him and trust in him, and that was just key for us” [A + T+] (mother of a 6-year-old girl).

Parents described committed, dedicated HCPs who worked beyond their obligations. A mother recalls: “[My child] was a very, .., recalcitrant patient … she was pretty much difficult the whole time .., but they were amazing, you know, they really tried to understand and they really tried
### Table 3 Illustrative quotes of subthemes identified among parents of childhood cancer survivors’ health-care and communication experience with health-care professionals

| Theme | Quotes | Path |
|-------|--------|------|
| **Interactions** | “He always takes the time to talk to us and talk to [my son], and [my son] has got a good relationship with him so he’s very open with him, and it’s like if I was moving towns it would be major concern because there’s a real good, I guess a relationship and a relationship of trust there.” Mother of a 6-year-old boy | I + T + |
| Careful explanations | “I understand Oncology’s very busy, but they were terrible at answering the [nurses] girl’s pagers or coming back and when they’d, when they finally rang the girls, the girls, they’d say, and obviously it would be the Registrars, they were like ‘well she’s not an active cancer patient, so it’s nothing to do with us’, but they were Oncology-based questions.” Mother of a 2-year-old boy | I-E rationalizing |
| Participative | “Um I’m a pretty upfront type of person and I was told very early on in the piece that I was her advocate and she cannot speak for herself so I need to speak for her.” Mother of a 7-year-old girl | I + E |
| Contactable and responsive to needs | “Look really good actually, because the hospital did a really good job of communicating, so even now letters, when we go and see someone, letters are sent to the referring GP, so we are always in the loop, and because they have had such an intense relationship with [my son], they are very on the ball and you know, treat him very well. So you know, again I do not have an issue at all, they have been very supportive and put his needs, you know, managed his needs very well.” Mother of a 4-year-old boy | I + T + |
| **Negative interactions** | “We were generally happy umm and like I said there were just two incidences were there was an issue with umm his medication, oh that he was on at the time, so umm obviously very unhappy and I think we feel a bit umm, what’s the word, umm like it wasn’t really resolved. I do not know that it was actually ever really resolved.” Mother of a 6-year-old boy | I-T |
| **Lacking guidance** | “You know you think you are going to be excited about that time but you are actually sh***ing yourself because now all of a sudden you are on your own and nobody seems to care, you are just out the door and okay onto the next. So there’s no follow-up, there’s no nothing, other than you know your MRIs but that’s just a case of you know telling you what the results are, it’s not telling you what you can do.” Mother of a 6-year-old boy | I-T |
| **Attitude** | “I personally think he did his best to make sure that we were fully informed of what was going on and what was being administered and what the risks were and all that sort of thing. I would say that that was a high quality [experience].” Mother of a 2-year-old girl | I + A + |
| Great expertise and care | “They were on top of it, they were very professional. There was not a day that you know, even if we called about that they would get back to us as soon as possible. And even just recently, I wanted the doctors to talk to [my son], that he’s overdoing it, that he’s just full on. And like they did not even do me in, they just said they are a bit concerned, they brought it as if they were concerned about… Yeah, so they were amazing.” Mother of a 6-year-old boy | I + A + |
| Committed and dedicated HCPs | “So there were lots of good things but there were lots of things that were really poor in the care that we received and again I think when you are in a hospital where it’s a teaching hospital and you have got doctors on rotations and as a parent you very, very quickly learn to become across everything and you learn to get a thick skin and you learn to question things.” Mother of a 15-year-old boy | I + T + |
| **Mistrust and disappointments** | “There were times where obviously I was less stressed than others due to different things that had to happen with her, umm but as the time went on, umm particularly in hospital, I, yeah I grew the confidence [sic] and I was very umm very happy with what they were telling me and what they were doing with her.” Mother of a 12-year-old girl | A-I + T + |
| Treatment uncertainty | “There were times where obviously I was less stressed than others due to different things that had to happen with her, umm but as the time went on, umm particularly in hospital, I, yeah I grew the confidence [sic] and I was very umm very happy with what they were telling me and what they were doing with her.” Mother of a 12-year-old girl | A-I + T + |
| Trust in HCPs | “I’m in a pretty upfront type of person and I was told very early on in the piece that I was her advocate and she cannot speak for herself so I need to speak for her.” Mother of a 7-year-old girl | I + E |
| **Trust** | “He’s always going to have to be monitored, like this is not a once you get to five years in remission you are good kind of thing. Umm so we are always going to have it hanging over our heads. Umm but for the next eight years at least, we have got the paediatric team behind us and they have been fantastic so it’s umm, I think we tend not to think about it too much, other than you know oh we have got an MRI scheduled, or that kind of thing.” Mother of a 3-year-old boy | T + E follow-up |
| **Engagement** | “Oh, I was one of those people that really, uh, when we first got there, I was googling and, and my husband had to just, he sort of just said to me: ‘You need to stop doing that because you are just, you know, feeding my, you know, feeding my fear of it’ and so it, um, it got to the point where I just, literally just said to the doctors like: ‘I trust in what you say and I really honestly asked for the, like, need-to-know, like do I need to know this or do I not?’” Mother of a 7-year-old boy | T + E medio + |
| Managing information needs | “You know you think you are going to be excited about that time but you are actually sh***ing yourself because now all of a sudden you are on your own and nobody seems to care, you are just out the door and okay onto the next. So there’s no follow-up, there’s no nothing, other than you know your MRIs but that’s just a case of you know telling you what the results are, it’s not telling you what you can do.” Mother of a 6-year-old boy | I-T |
| **Proactive** | “Look really good actually, because the hospital did a really good job of communicating, so even now letters, when we go and see someone, letters are sent to the referring GP, so we are always in the loop, and because they have had such an intense relationship with [my son], they are very on the ball and you know, treat him very well. So you know, again I do not have an issue at all, they have been very supportive and put his needs, you know, managed his needs very well.” Mother of a 4-year-old boy | I + T + |
| **Follow-up is important** | “Oh, I was one of those people that really, uh, when we first got there, I was googling and, and my husband had to just, he sort of just said to me: ‘You need to stop doing that because you are just, you know, feeding my, you know, feeding my fear of it’ and so it, um, it got to the point where I just, literally just said to the doctors like: ‘I trust in what you say and I really honestly asked for the, like, need-to-know, like do I need to know this or do I not?’” Mother of a 7-year-old boy | T + E medio + |
| **Rationalizing** | “I understand Oncology’s very busy, but they were terrible at answering the [nurses] girl’s pagers or coming back and when they’d, when they finally rang the girls, the girls, they’d say, and obviously it would be the Registrars, they were like ‘well she’s not an active cancer patient, so it’s nothing to do with us’, but they were Oncology-based questions.” Mother of a 2-year-old boy | I-E rationalizing |

Legend: À-, negative attitude; À+, positive attitude; I-, negative interaction; I+, positive interaction; T-, lowered degree of trust; T+, promoted degree of trust; Eproactive+, proactively engaged in care; Efollow-up, follow-up care was considered important; Einfo+, information needs were managed; Erationalizing, disappointments were rationalized
to work with her, even if it took them extra time…” [I + A+] (mother of an 8-year-old girl).

**Negative attitude**

Parents seemed to struggle most with what one father described as the “evil necessity” (father of a 16-year-old girl) of treatment and its associated uncertainties, for example, how long treatment would last and what types of treatment the child would need. A mother explained:

“…going on the clinical trial was really scary cause [sic]… for me it kind of felt like they were using my kid as a trial, you know as a mouse, testing out medication” [A-T-] (mother of an 11-year-old boy).

Parents’ attitudes towards their child’s treatment were mitigated by the perceived high expertise and clear communication skills of HCPs (example in Table 3).

**Trust and engagement**

Parents’ degree of trust in HCPs seemed to impact the way they engaged in their child’s health care (quotes T ± E). With higher trust, parents seemed to manage their information needs more easily (E\text{info}), followed HCPs recommendations (E\text{proactive}), and understood that LTFU care is essential (E\text{follow-up}). With lower trust, parents sought out more information (E\text{info}), advocated for their child (E\text{proactive}), and rationalized what happened (E\text{rationalizing}). It is important to note that managing information needs and proactive engagement in care was seen to differ in its form depending on higher or lower trust.

**Building trust**

Increased trust seemed to build upon positive interactions and positive attitudes. Instructions received regarding treatments were followed (T + E\text{proactive}). For example, parents stated:

“I felt quite safe with them and that they would do whatever they could for her...we just put all our faith in the doctors and the nurses and whatever they said that’s what we did” [A + T + E] (mother of a 15-year-old girl).

With a trusting HCP-parent relationship, satisfying their information needs seemed to be more manageable for parents as it gave them a sense of security to having received trusted information (T + E\text{info}). They were able to limit themselves to essential information, take distance, and focus on being a parent to their child (example in Table 3).

A trusting HCP-parent relationship also fostered the understanding that survivorship care is a necessity. A father described how he perceives the follow-up appointments of his son not as an additional burden:

“That’s just part of our life now. I think we revisit them [the child’s oncology team] once every six months or so, I think, so yeah, it’s not a, it doesn’t feel like it’s an ongoing thing, there’s no real sort of extra care on that side” [E\text{follow-up}] (father of a 4-year-old son).

**Threatened trust**

Decreased trust seemed to derive from negative interactions and negative attitudes. Trust was not self-evident for many parents and needed to be built over time: “Trust and belief was a big one. When he was first diagnosed, I had none of that, I was just trying to get a grip on what was happening” [A-T-] (mother of a 6-year-old son).

---

**Fig. 2** Model of trust and engagement for the parent-clinician relationship during childhood cancer treatment and survivorship, displaying the role of interactions with health-care professionals and attitudes towards health care. Legend: Colour shadings for positive experiences = green; negative experiences = orange; parent’s degree of trust (low-high) = light–dark blue; type of engagement in care: based on positive experiences = green, based on negative experiences = orange, variant by parents’ degree of trust = blue. Solid lines represent the pathways of reciprocal interplays.
A substantial proportion of parents recalled having been disappointed along the cancer journey (Table 2, example in Table 3).

Lower trust seemed to promote more proactive parental behaviours in their child’s health care, such as seeking out additional information (E info), advocating for their child’s needs during treatment, and reaching out for help during follow-up care (E proactive), for example, to manage late effects. A mother explained:

“He nearly was given a fatal dose of the chemotherapy, … it was late at night and the nurse had gotten it wrong um so yeah that’s why I was always just there to know what was going on” [I-T-E proactive] (mother of a 15-year-old son).

Parents justified and rationalized difficult situations, such as being confronted with apparent medical mistakes or unsupportive behaviours of HCPs (E rationalizing). They attributed it to only one specific doctor or nurse who was the exception or to environmental aspects of the hospital setting. Rationalizing seemed to be a concrete strategy for parents to maintain a trusting relationship with HCPs:

“There’s nothing you can do, it’s already happened, so you know it’s disappointing, but at the same time, you’ve got nurses who are overworked and doing double shifts and doctors who write like, I couldn’t even read it myself” [I-E rationalizing] (mother of a 6-year-old son).

Discussion

Australian parents’ experiences with HCPs were predominantly positive. Parents were confident in HCPs’ expertise, valued their dedication, and were especially grateful for their continuous availability. However, parents also recounted negative interactions and needing more specific guidance, especially after treatment completion. We propose a model of parent-practitioner communication to explain how parents’ perceived interactions and attitude towards HCPs impact their levels of trust and their health-care engagement.

Previous research regarding the communication experiences with HCPs goes in line with our model: using unfamiliar jargon, communicating in a paternalistic manner, and not engaging the patient in treatment planning and decision-making have been identified as key drivers for negative experiences [20]. Negative interactions have been seen to be appraised as threats to the relationship [21], and reduced trust drove parents to act as advocates for their child [4]. Attitude towards treatment – for example, the belief to benefit – has been associated with the quality of the relationship [7].

Our findings further echo with findings from a meta-synthesis regarding the parent-practitioner relationship in childhood cancer [4] and a longitudinal study describing parents’ engagement in “containment work” [21] p.1303: Carers cognitively engaged in “meaning making” as a tool to maintain trust in the relationship. Also in our study, parents rationalized negative experiences and attributed apparent medical mistakes to pressure on clinicians or blamed the medical system. “Meaning making” can be a successful strategy to reduce discrepancies and to adjust to stressful situations [21–23]. This might be functional when disagreements or mistakes are relatively minor and associated with low costs. In more complex situations such as treatment decision-making in the context of bad news (e.g. disease progression/poor response) or uncertainty (e.g. phase I trial), the strategy might be ineffective to reconcile parents’ dissatisfaction with care and detrimental to the parent-HCP relationship. Previous research showed that trust is fundamental for ongoing collaboration and communication with HCPs [7].

Many parents in this study emphasized not having received enough support in the early post-treatment period regarding ongoing care. Parents’ narrative around health care may impact the survivors’ interactions with, and attitudes towards, the health system later on, which may affect their health literacy and attendance of LTFU care [24–27].

Future directions

Research

Our model could become instrumental in addressing clinically relevant research questions. However, the model needs further testing in the wider population to assess model fit. For this, quantitative measures of attitudes, trust, and engagement could be assessed longitudinally. Future studies evaluating clinical and communication-related interventions would benefit from assessing those key concepts, because they may help identify the most impactful ways to support families’ health-care engagement throughout the entire trajectory.

The quality of parents’ interactions with HCPs has been identified as predictive of their satisfaction with their child’s health care [28, 29]. It would be important to establish the flow-on effects of parents’ levels of trust and engagement for their later mental health, given the long-lasting emotional impact years into their child’s survivorship [30–32].

Clinical practice

HCPs who experience difficulties effectively engaging parents in the health-care process should consider trust as a barrier. Recent research suggests that clinicians will need to consider addressing the cumulative impact of the overt interactions they have had with families and the “implicit” or non-verbal communication parents may have received or perceived over the course of their child’s diagnostic period and treatment [28]. Communication training for trainee and early-career HCPs that is codesigned with consumers (both patients and their family members) may be a particularly effective
model [33]. Research is also starting to explore the role of artificial intelligence technologies in enhancing HCPs’ communication skills [34, 35].

For parents in our study, the perception that someone was available and cared, as well as receiving explicit recommendations, helped them to navigate through treatment and the early post-treatment period. Because parents felt support ended prematurely, HCPs could focus on prioritizing communication around transitioning to other specialists [36] and to primary care to reduce parents’ sense of being “abandoned” by the system.

Strengths and limitations

To our knowledge, this is the first study to explore the parent-HCP health-care and communication experience in Australia. A major strength of our study was that we explored parents’ spontaneously reported experiences with HCPs and were hence able to identify the most salient elements to them. Previous studies have been criticized to overemphasize parents’ difficulties in interacting with HCPs because participants were recruited through advocacy and self-help groups or parents of survivors authored the papers, without reflecting how their experiences might have shaped their research [4]. In the present study, the primary analyst (JB) had a naïve understanding of the Australian context, which is valuable when using grounded theory. Those strengths address some of the weaknesses of previous research concerning parent-HCP communication [4].

Our findings should be considered in the context of several limitations. The data was collected as part of a longitudinal intervention study, and the opt-in rate was relatively low. It is possible that only parents who had reasonably positive health-care experiences self-selected into the study. Our sample was also highly educated [37], which might signify higher levels of health literacy and capacity to negotiate the health-system and doctor-patient interactions. The short time after successful treatment completion might lead to parents focusing on the positive outcome and expressing their gratitude. We have seen that parents reported less distress with declining perceived risk of relapse [38]. Parents’ perspectives might change when difficulties, such as late effects, arise later. Bereaved parents’ recollections of their interactions with HCPs may differ too.

Conclusion

Parents built trust over time with HCPs based on their interactions and attitudes. Depending on the degree of trust parents had in their child’s HCPs, parents either followed recommendations more closely (high trust) or instead focused on being advocates for their child (low trust). Parents minimized the impact of negative HCP interactions on their child’s care through internal, rationalizing processes. Our findings demonstrate the flexibility and resilience of parents in acting as a buffer between HCP interactions and their child in dynamic ways.

Acknowledgements The authors thank the parents who participated in this study and wish to acknowledge the valuable contributions of Emma Doolan, Sarah Ellis, Holly Evans, Kate Marshall, Sanaa Mathur, Eden Robertson, and Helen Wilson from the Behavioural Sciences Unit (Kids Cancer Centre, Sydney Children’s Hospital).

Funding information The CASCADE project is funded by Cancer Australia, Priority-Driven Collaborative Cancer Research Scheme (APP1065428). U.M. Sansom-Daly is supported by an Early Career Fellowship from the Cancer Institute of NSW (ID: 14/ECF/1–11) and an Early Career Fellowship from the National Health and Medical Research Council of Australia (NHRMC, APP1111800). C.E. Wakefield is supported by a Career Development Fellowship from the NHMRC (APP1143767). The Behavioural Sciences Unit is proudly supported by the Kids with Cancer Foundation, the Kids Cancer Alliance, and Cancer Council NSW (PG16–02) with the support of the Estate of the Late Harry McPaul. J. Baenziger is supported by the Swiss National Science Foundation (SNSF, P1LP1I_178330).

References

1. Sultan S, Leclair T, Rondeau E, Burns W, Abate C (2016) A systematic review on factors and consequences of parental distress as related to childhood cancer. Eur J Cancer Care 25(4):616–637. https://doi.org/10.1111/ecc.12361
2. Hewitt M, Weiner SL, Simone JV (2003) The trajectory of child-hood cancer care. In: Childhood cancer survivorship: improving care and quality of life. The National Academies Press, Washington D.C., pp 37–48
3. Alderfer MA, Navsaria N, Kazak AE (2009) Family functioning and posttraumatic stress disorder in adolescent survivors of childhood cancer. J Fam Psychol 23:717–725. https://doi.org/10.1037/a0015996
4. Davies S, Young B, Salmon P (2016) Towards understanding problems in the parent-practitioner relationship when a child has cancer: meta-synthesis of the qualitative literature. Psycho-oncology:1252 –1260. https://doi.org/10.1002/pon.4285
5. Coyne I, Amory A, Kieman G, Gibson F (2014) Children’s participation in shared decision-making: children, adolescents, parents and healthcare professionals’ perspectives and experiences. Eur J Oncol Nurs 18(3):273–280. https://doi.org/10.1016/j.ejon.2014.01.006
6. Hoekstra-Weebers JEHM, Jaspers JPC, Kamps WA, Klip EC (2001) Psychological adaptation and social support of parents of pediatric cancer patients: a prospective longitudinal study. J Pediatr Psychol 26(4):225–235
7. Fuertes JN, Toporovsky A, Reyes M, Osborne JB (2017) The physician-patient working alliance: theory, research, and future possibilities. Patient Educ Couns 100(4):610–615. https://doi.org/10.1016/j.pec.2016.10.018
8. Michel G, Gianinazzi ME, Eiser C, Bergstrasser E, Vetsch J, von der Weid N, Kuehni CE, Group SPO (2016) Preferences for long-term follow-up care in childhood cancer survivors. Eur J Cancer Care 25(6):1024–1033. https://doi.org/10.1111/ecc.12560
9. Vetsch J, Rueegg CS, Mader L, Bergstrasser E, Rischewski J, Kuehni CE, Michel G, Group tSPO (2016) Follow-up care of young childhood cancer survivors: attendance and parental
involvement. Support Care Cancer 24(7):3127–3138. https://doi.org/10.1007/s00520-016-3126-6
10. Doshi KK, A. E.; Hocking, M. C.; Derosa, B. W.; Schwartz, L. A.; Hobbie, W. L.; Ginsberg, J. P.; Deatrick, J. (2014) Why mothers accompany adolescent and young adult childhood cancer survivors to follow-up clinic visits. J Pediatr Oncol Nurs 31(1):51–57. https://doi.org/10.1177/1034542113181111
11. Baenziger J, Roser K, Mader L, Christen S, Kuethi CE, Gumn-Pause F, Tanner EM, Michel G (2018) Can the theory of planned behavior help explain attendance to follow-up care of childhood cancer survivors? Psychooncology. https://doi.org/10.1002/pon.4680
12. Vetsch J, Fardell JE, Wakefield CE, Signorelli C, Michel G, McLoone JK, Walwyn T, Tapp H, Truscott J, Cohn RJ, Group Ass (2017) “Forewarned and forearmed”: long-term childhood cancer survivors’ and parents’ information needs and implications for survivorship models of care. Patient Educ Couns 100(2):355–363. https://doi.org/10.1016/j.pec.2016.09.013
13. Vetsch J, Rueegg CS, Gianinazzi ME, Bergsträsser E, von der Weid NX, Michel G, for the Swiss Paediatric Oncology G (2015) Information needs in parents of long-term childhood cancer survivors. Pediatr Blood Cancer 62 (5):859–866. doi:https://doi.org/10.1002/pbc.25418
14. Wakefield EG, Sansom-Daly UM, McGill BC, Ellis SJ, Doolan EL, Robertson EG, Mathur S, Cohn RJ (2016) Acceptability and feasibility of an e-mental health intervention for parents of childhood cancer survivors: Cascade. Support Care Cancer 24:2685–2694. https://doi.org/10.1007/s00520-016-3077-6
15. Morrow GR, Chiarello RJ, Derogatis LR (1978) A new scale for assessing patients’ psychosocial adjustment to medical illness. Psychol Med. 8(44):605. https://doi.org/10.1017/s003329170001818x
16. Bradley EH, Curry LA, Devers KJ (2007) Qualitative data analysis for health services research: developing taxonomy, themes, and theory. Health Serv Res 42(4):1758–1772. https://doi.org/10.1111/j.1475-6773.2006.00684.x
17. Robertson EG, Sansom-Daly UM, Wakefield CE, Ellis SJ, McGill BC, Doolan EL, Cohn RJ (2016) Sexual and romantic relationships: experiences of adolescent and young adult cancer survivors. J Adolesc Young Adult Oncol 5(3):286–291. https://doi.org/10.1089/jayao.2015.0061
18. Nvivo - QSR international (2018) Run a coding comparison query. http://help-nv11.qsrinternational.com/desktop/procedures/run_a_coding_comparison_query.htm.
19. Santiago Delefosse M (2011) An embodied-socio-psychological perspective in health psychology? Soc Personal Psychol Compass 5(2):220–230. https://doi.org/10.1111/j.1751-9004.2011.00345.x
20. Rocque R, Leanza Y (2015) A systematic review of patients’ experiences in communicating with primary care physicians: intercultural encounters and a balance between vulnerability and integrity. PLoS One 10(10):e0139577. https://doi.org/10.1371/journal.pone.0139577
21. Davies S, Salmon P, Young B (2017) When trust is threatened: qualitative study of parents’ perspectives on problematic clinical relationships in child cancer care. Psycho-Oncology 26(9):1301–1306. https://doi.org/10.1002/pon.4454
22. Park CL. (2010) Making sense of the meaning literature: an integrative review of meaning making and its effects on adjustment to stressful life events. Psychol Bull 136(2):257–301. https://doi.org/10.1037/a0018301
23. Lyons AC, Chamberlain K (2006) Being ill. In: Lyons AC, Chamberlain K (eds) Health Psychology: A critical introduction. Cambridge University Press, Cambridge, pp 279–318. https://doi.org/10.1017/CBO9780511807985.010
24. Lin M, Sansom-Daly UM, Wakefield CE, McGill BC, Cohn RJ (2017) Health literacy in adolescents and young adults: perspectives from Australian Cancer survivors. J Adolesc Young Adult Oncol 6(1):150–158. https://doi.org/10.1089/jayao.2016.0024
25. May EA, McGill BC, Robertson EG, Anazodo A, Wakefield CE, Sansom-Daly UM (2018) Adolescent and young adult cancer survivors’ experiences of the healthcare system: a qualitative study. J Adolesc Young Adult Oncol 7(1):88–96. https://doi.org/10.1089/ jayao.2017.0015
26. Sansom-Daly UM, Lin M, Robertson EG, Wakefield CE, McGill BC, Girgis A, Cohn RJ (2016) Health literacy in adolescents and young adults: an updated review. J Adolesc Young Adult Oncol 5(2):106–118. https://doi.org/10.1089/jayao.2015.0059
27. Signorelli C, Wakefield CE, Fardell JE, Brierley ME, Darlington AS, Williamson J, Downie P, Cohn RJ, Group Ass (2019) Perceptions of future health and cancer risk in adult survivors of childhood cancer: implications for engagement in follow-up care. Cancer 125(6):1008–1009. https://doi.org/10.1002/cncr.31934
28. Sisk BA, Kang TJ, Mack JW (2018) How parents of children with cancer learn about their children’s prognosis. Pediatrics 141(1). https://doi.org/10.1542/peds.2017-2241
29. Sisk BA, Mack JW, Ashworth R, DuBois J (2018) Communication in pediatric oncology: state of the field and research agenda. Pediatr Blood Cancer 65(1). https://doi.org/10.1002/pbc.26277
30. McKenzie SE, Curle C (2012) ‘The end of treatment is not the end’: parents’ experiences of their child’s transition from treatment for childhood cancer. Psycho-Oncology 21:647–654. https://doi.org/10.1002/pon
31. Vetsch J, McGill BC, Sansom-Daly UM, Hetherington K, Ellis SJ, Marshall KH, Wakefield CE (2019) Comorbidity of distress experienced by parents of childhood cancer survivors points to the importance of understanding transdiagnostic cognitive-affective mechanisms. Acta Oncol 58(2):189–190. https://doi.org/10.1080/0284186X.2018.1512157
32. Lown EAP, Farya, Schwartz LA, Rosenberg AR, Jones B (2015) Psychosocial follow-up in survivorship as a standard of care in pediatric oncology. Pediatr Blood & Cancer 62(S5):S531–S601. https://doi.org/10.1002/pbc.25783
33. Wiener L, Shaw Weaver M, Bell CJ, Sansom-Daly UM (2015) Threading the cloak: palliative care education for care providers of adolescents and young adults with cancer. Clinical Oncology in Adolescents and Young Adults 5:1–18. https://doi.org/10.2147/COYA.A49176
34. Ryan P, Luz S, Albert P, Vogel C, Normand C, Kennedy E, Elwyn G (2019) Using artificial intelligence to assess clinicians’ communication skills. BMJ 364:k1161. doi:https://doi.org/10.1136/bmj.1161
35. McGill BC, Wakefield CE, Sethu V, Epps J (2019) Collaboration between engineering and the behavioural sciences is critical for the advancement of artificial intelligence in medicine. BMJ rapid response. Doi:https://www.bmj.com/content/364/bmj.l161/rr-1
36. Koch KD, Jones BL (2018) Supporting parent caregivers of children with life-limiting illness. Children 5(7). https://doi.org/10.3390/children5070085
37. Australian Bureau of Statistics (2018) 6227.0 - Education and Work, Australia, May 2018: vol Series. Commonwealth of Australia, Canberra
38. Wakefield CE, McLoone JK, Butow P, Lenthen K, Cohn RJ (2010) Parental adjustment to the completion of their child’s cancer treatment. Pediatr Blood Cancer 56(4):524–531. https://doi.org/10.1002/pbc.22725

Publisher’s note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.