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Parents' experiences of whole-body MRI-based surveillance for their child with genetic cancer risk: a longitudinal qualitative study

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Abstract

Broad genomic screening in pediatric oncology is increasingly identifying children with genetic cancer risk indicating intensive, lifelong surveillance. While this may improve early cancer detection, families face complex psychosocial challenges with unclear implications for adherence. We aimed to explore parents' experiences of ongoing surveillance for their child with a multi-organ genetic cancer risk condition, including how these experiences changed over time. Parents'/caregivers' of children (<18yrs) participating in WBMRI-based surveillance completed interviews at enrolment and following surveillance events. Interviews were transcribed and analyzed using reflexive thematic analysis. Thirteen parents (median age=41.4yrs; 54% female) of 13 children (median age=8.1yrs) participated in 33 interviews (median=2, range=1-5). Children had germline pathogenic/likely pathogenic variants in *TP53* (n=10), *BLM* (n=2; biallelic), and *RB1* (n=1) genes. Parents described surveillance as characterized by cyclical procedural and outcome-related uncertainty influenced by additional psychosocial stressors. Coping strategies evolved over time and involved emotional (e.g. compartmentalization) and practical strategies (e.g. simulating procedures). Administrative burdens, care co-ordination, and persistent fear of cancer occurrence remained significant challenges. Parents' initially described children as focused on procedural aspects of surveillance, for some these perceptions shifted across repeated surveillance with some children showing increased cancer-related distress. A desire to benefit their child, seek reassurance, and contribute to research motivated ongoing engagement despite challenges. Parents perceive surveillance as worthwhile, despite emotional and practical burdens. Multidisciplinary care models that streamline communication and integrate proactive psychosocial and dedicated psychological support may reduce ongoing challenges.

1. INTRODUCTION

Precision medicine studies indicate 10-18% of children, adolescents, and young adults with cancer carry a pathogenic or likely pathogenic variant (P/LPV) in a cancer predisposition gene associated with genetic cancer risk, some of which will require lifelong cancer surveillance (1). As precision medicine becomes standard practice in pediatric oncology, this number is expected to grow(2, 3). For conditions such as Li-Fraumeni Syndrome (LFS), there is international consensus on pediatric cancer risk management strategies(4-7). However, for many conditions, surveillance protocols lack evidence of benefit, relying on expert consensus(8). Families and clinicians must therefore grapple with uncertainty regarding the most beneficial approach.

For conditions involving multiple organs, surveillance includes regular clinical examinations and imaging, such as abdominal ultrasound and whole-body-MRI (WBMRI). WBMRI is an effective surveillance tool offering multi-organ screening while preventing exposure to ionizing radiation. In adults with LFS, WBMRI is generally well tolerated(9, 10), although some patients report anxiety before appointments(11). However, WBMRI often identifies incidental findings that are benign, but which still require further imaging, interval follow-up, subspecialty review, or biopsy, creating additional burdens(12-14). Regular

WBMRI in pediatric populations also often involves the need for sedation or general anesthesia, which may cause additional distress regarding anesthesia-related risks(15).

Few studies have examined psychosocial impacts of regular cancer surveillance on children with genetic cancer risk and their families. Yet surveillance protocols can be demanding, with ongoing practical, emotional, and financial burdens. Routine care for children with genetic cancer risk is often fragmented without well-established care models making surveillance access challenging(16). Families may already be emotionally impacted by cancer diagnoses in the family or facing additional psychosocial challenges(17-21). A small number of recent qualitative research has highlighted anticipatory anxiety, distress related to procedures, and logistical challenges (22-24). No studies have examined how experiences evolve over time or focused specifically on conditions where WBMRI is indicated. Insights into parents' experiences of surveillance for pediatric genetic cancer risk will inform family-centered care and refinement of surveillance strategies to optimize clinical outcomes whilst reducing negative psychosocial impacts.

1.1 Research Questions

1. What are parents' perspectives and experiences of their child's participation in regular WBMRI-based surveillance for pediatric genetic cancer risk?

2. How do these experiences change over time?

2. METHODS

2.1 Participants and Study Design

The Surveillance in Multi-Organ Cancer predisposition syndromes in pediatrics (SMOC-Junior) study recruited children aged ≤ 18 with a known P/LPV in a cancer predisposition gene conferring multi-organ tumor risk requiring WBMRI surveillance, no active cancer diagnosis, ECOG performance status of 0 or 1, and an expected lifespan > 3 years. SMOC-Junior was open at two Children's Hospitals in New South Wales, Australia. Children were offered WBMRI and additional multi-modal surveillance procedures customized by genotype following international expert panel consensus and consultation with eviQ risk management guidelines. Following procedures, study coordinators arranged appointments for result-return and further investigation, if necessary.

SMOC-Junior included a prospective, longitudinal, mixed-methods psychosocial component. Parents of children enrolled on SMOC-Junior were invited to complete semi-structured interviews following enrolment and after each surveillance procedure. This manuscript reports data collected during parent interviews.

2.2 Recruitment and data collection

All families enrolled in SMOC-Junior were enrolled in the psychosocial component if they had sufficient English language skills and did not present with severe physical or mental health concerns (assessed by the clinical team). The psychosocial study coordinator (JDH) contacted families to confirm participation and arrange interviews, liaising with clinical teams to co-ordinate interviews after each surveillance procedure. Interviews were optional; parents could decide not to participate in an interview and still participate in further interviews. If a participant could not be contacted after three attempts, they were considered unreachable but were still invited for further interviews. If a child was diagnosed with cancer during surveillance, participation in the psychosocial component was paused, with the option for parents to complete an interview prior to this pause and recommence participation once surveillance resumed. One researcher (JDH) conducted and audio recorded interviews and transcribed recordings verbatim using Microsoft Teams.

2.3 Measures

Parent demographic and child clinical data were collected as part of the broader SMOC-Junior study. A multi-disciplinary expert panel comprising psychologists, genetic counsellors, clinical geneticists, pediatric oncologists, and psychosocial researchers developed and pilot-tested interview guides; one for initial interviews and one for follow-up interviews (Supplementary Table 1). Expectations, experiences of recent surveillance procedures, receipt of results, and opinions towards SMOC-Junior and regular surveillance more broadly were explored.

2.4 Data analysis

Quantitative data were summarized using descriptive statistics in SPSS (V30.0.0.0)(25). Qualitative data were analyzed using reflexive thematic analysis within a pragmatic-constructionist epistemological framework(26, 27). We used a whole population sampling approach, inviting all eligible participants and continuing data collection for the entire study period.

Each participant's set of interviews was treated as an individual 'case' and reviewed collectively. One psychosocial researcher (JDH) with postgraduate training in qualitative research and no prior relationship with participants undertook familiarization by reviewing all transcripts alongside original audio. Using NVivo (QSR International Pty Ltd. Version 14, 2024), JDH conducted an initial round of inductive coding of individual transcripts, followed by development of case summaries capturing key experiences and within-case change over time, also inductively coded. Initial codes were discussed and refined with two additional psychosocial researchers (KH, MP). JDH then conducted further iterative, reflexive coding to develop interpretive codes capturing shared and divergent patterns of meaning. Ongoing reflexive discussions were conducted throughout analysis to examine assumptions influencing data interpretation and to refine and name final themes and subthemes.

3. RESULTS

3.1. Participants

Of 17 families deemed eligible for inclusion, 16 opted in (94%), 12 had at least one parent participate in an interview (71%). Thirteen parents (Table 1) of 13 children (Table 2) participated in 33 interviews.

3.2 Qualitative themes

Theme 1: Cyclical uncertainty

Parents characterized their child's surveillance as an ongoing cycle of procedural and

outcome-related uncertainty (Table 3).

1.a. Anticipatory and outcome-related uncertainty

Parents described struggling with 'limbo' periods, they worried while waiting for scans to happen, waiting for results, or waiting for investigation of incidental or indeterminate findings. These worries stemmed from fears their child would be diagnosed with cancer. Some parents described these worries as "always there" (ID1, father, *TP53*), even between surveillance events.

1.b. Procedural uncertainty

Parents described significant procedural uncertainty, particularly leading up to and during scans. These concerns centered on whether they/their child would cope emotionally or co-operate, and whether procedures, especially MRIs with general anesthetic, would be completed safely and successfully. For some, this was informed by prior distressing experiences: "they've had to make us pin her down. It was horrible" (ID1, father, *TP53*).

Parents also indicated healthcare professionals could impact how smoothly procedures went. Difficult encounters, such as when staff struggled with cannulation, could heighten distress or trigger behavioral outbursts in their child. Others described not 'fitting in' with traditional clinical cancer settings, navigating health systems that were not designed for them.

1.c. Complex and fluctuating risk perception in the face of uncertainty

During ongoing surveillance, parents' interpretations of their child's cancer risk were complex and shaped by how they engaged with uncertainty. For some, scans heightened perceptions of cancer risk and triggered anxiety and distress. For others, scans provided reassurance or had positive impacts, even if only temporarily.

Differences in risk perception were related to how parents managed information and uncertainty. Some engaged in close monitoring of clinical encounters, interpreting subtle changes in processes, communication, or clinician demeanor as indicators of concern: "I just saw the face drop, of the technician…I knew in that moment something was not right" (ID2, mother, *TP53*). These parents often anticipated worst-case outcomes in response to ambiguity or inconsistent processes, desiring clear,

transparent communication to help manage uncertainty. Others preferred a more avoidant approach, suggesting “being obliviously unaware is a blessing in disguise” (ID3, mother, non-*TP53*).

Theme 2: Navigating Surveillance amid additional stressors

Additional stressors intersected with surveillance demands, sometimes compounding emotional and practical challenges and reducing parents’ ability to cope.

2.a. Parent and family level psychosocial challenges

Surveillance unfolded alongside broader psychosocial challenges for parents. Pre-existing mental health challenges, financial insecurity, housing instability, and relationship breakdowns were described as intensifying demands of coordinating surveillance-related care for their child: “it’s hard…she’s 100% in my care but I do like to keep him [father] informed and he doesn’t really believe in all of the secondary cancers” (ID4, mother, non-*TP53*).

School-related challenges associated with lack of understanding of their child’s condition, including inflexibility around missed attendance or bullying, compounded pressures for some: “we recovered alright…the next challenge came with being bullied at school” (ID5, mother, *TP53*).

2.b. Child health complexities

Some parents described their child having additional health complexities further complicating surveillance. Neurodivergence like autism spectrum disorder or attention deficit disorder intensified procedural challenges like administering general anesthesia. For parents of children with multi-systemic genetic cancer risk conditions, interventions beyond cancer monitoring, like sun protection and weight management, added to the burden of navigating an already challenging surveillance landscape.

In some cases, surveillance led to a new cancer diagnosis, introducing an additional layer of emotional and practical burden. One parent described the sadness accompanying this shift: “it’s very disheartening, quite sad” (ID5, mother, *TP53*).

2.c. Reactivating past trauma and loss

For some parents, surveillance was a reminder of past trauma or loss, reactivating feelings of fear and grief. One parent who had already lost a child to cancer described her child’s first MRI as “incredibly triggering…I was really scared because of what was found when [sibling’s name] had an MRI” (ID2, mother, *TP53*). Similarly, parents whose child had a personal history of cancer described how medical trauma shaped their child’s negative behavioral responses to hospital settings. Additionally, previous adverse events or negative experiences during scans could cause significant anticipatory anxiety before procedures.

2.d. The repeated burden of being the ‘expert parent’

Parents described assuming an ‘expert parent’ role, carrying primary responsibility for coordinating care, appointments, managing referrals, and advocating for their child across health systems. This administrative labor was ongoing and intensive, requiring sustained vigilance and organization. Some reported feeling unheard or dismissed, having to continually advocate for their child to staff: “all the specialists had no idea what I was talking about. So, there was a level of education that I had to do” (ID3, mother, non-*TP53*). One parent described arguing with radiology staff on multiple occasions to stop them using gadolinium-based contrast in her child due to concerns related to possible risks for children with LFS: “I had to stand over [child’s name]'s body, she’s unconscious, and say I will not consent to the contrast being used. I had to fight to get them to follow what was recommended” (ID6, mother, *TP53*).

Theme 3: Emotional and self-protective coping

Parents described the emergence of psychological strategies aimed at managing outcome-related uncertainty and emotional challenges.

3.a. Taking it ‘one step at a time’

Parents emphasized the importance of compartmentalization, breaking down surveillance into manageable steps. This involved avoiding future-thinking, staying present, and remaining optimistic by “thinking positive thoughts” (ID4, mother, non-*TP53*). For some, this optimism was informed by previous surveillance experiences: “because we haven't had any bad news, I feel like it's going to be good news” (ID1, father, *TP53*). Participation in SMOC-Junior supported this protective coping approach by providing reassurance and reducing immediate worry: “the surveillance means I don’t feel worried, I feel reassured. There may come a time when I have to face really difficult things, but I don't go there” (ID6, mother, *TP53*).

Linked to this was acceptance of their child’s condition, this allowed parents to focus on what could be managed in the present: “In terms of what the results would be, that’s out of my hands…I just focus on being present” (ID6, mother, *TP53*).

3.b. Managing emotional overload through avoidant coping

When surveillance stress became overwhelming, parents described strategies aimed at managing emotional overload. For some, this involved avoidant strategies such as intentionally limiting exposure to emotional triggers or emotional numbing: “[My psychologist] allows me to feel numb…I think it’s important to just have that protection otherwise I honestly don’t think I would cope” (ID2, mother, *TP53*). Others focused on distractions to prevent fears from escalating.

3.c. Seeking external emotional support

Parents also emphasized the importance of not carrying the emotional load alone. Some used medication to manage anxiety, engaged in therapeutic activities, psychological support, and counselling. Others desired better access to this kind of support, particularly when waiting for results “it’s not nice

[waiting for results]…I need therapy. I definitely need that…I don't have one [psychologist]" (ID1, father, *TP53*) or expressed desires for embedded psychological support within surveillance: "whether you need to tap into it or not, having that availability… would set your mind at ease. It would be good to have that resourced" (ID5, mother, *TP53*).

Theme 4: Reclaiming control through practical coping

Despite ongoing challenges, parents described surveillance as a means of reclaiming control over their child's health, developing strategies to manage procedural uncertainty and directing focus to where their actions could influence outcomes.

4.a. Leveraging supportive healthcare structures

Many described highly valuing the co-ordination, practical support, and guidance they were provided by the clinical surveillance team, which helped parents feel better able to manage their child's care and relieved pressure associated with being the 'expert parent': "it's reassuring that I'm now no longer the only advocate for him. There are lots of other people now who can take responsibility and understand" (ID7, mother, *TP53*).

4.b. Mastering the surveillance process and taking on responsibility for outcomes

Parents described reclaiming control by mastering surveillance processes, practicing scans at home or the hospital with support from play specialists, and using toys, bribes or therapeutic techniques to manage procedural challenges. Some recognized the importance of shaping positive experiences to maintain adherence: "I knew if an experience is difficult and traumatic, then it gets harder and harder. But if we make it fun and she enjoys it, then it will stay easy" (ID6, mother, *TP53*). Over time, increased familiarity with procedures enhanced predictability and confidence for some, and parents developed strategies to help their child cope: "she laid on top of me on the table and we got great images. There was no screaming or panicking…every other time was a disaster" (ID3, mother, non-*TP53*).

However, parents also acknowledged that mastering surveillance processes brought pressure associated with a responsibility to ensure good outcomes: "I don't want her put through anything painful or traumatic, I want the tests to work, I want them to get clear images…often she's got to be fasting, but also have a full bladder...I'm trying to control a whole lot of different elements...so it's a high level of stress" (ID6, mother, *TP53*).

4.c. Proactive information seeking, planning, and advocacy

Parents described proactively seeking information, additional testing, and navigating logistical barriers to regain control and cope in periods of uncertainty: "I won't just sit and wait. I'll start asking questions and pushing people" (ID7, mother, *TP53*). Additionally, while most parents described having good understanding of SMOC-Junior, surveillance more broadly, and their child's condition, they also advocated for improved resources when they felt information was limited: "there wasn't a load of

resources on how we're going to prepare [child's name] for these appointments…there's enough information for us as adults… but for a child…maybe more resources" (ID8, father, *TP53*).

4.d. Encouraging risk-reducing, preventative health behaviors

Parents described focusing on aspects of their child's health within their influence. This included encouraging healthy lifestyle choices and avoidance of behaviors that increase cancer risk, while also remaining vigilant to potential symptoms.

However, some parents reflected that an emphasis on health behaviors could place unintended pressure on their child: "he's an obsessive type of individual. He'll monitor his steps, all that stuff…we're trying to keep that so it's not silly" (ID7, mother, *TP53*).

Theme 5: Making sense of and shaping child coping

In initial interviews, parents described their child as primarily concerned with procedural challenges. For some, these perceptions shifted over time as children grew older, medical interventions intensified, or cancer exposure increased.

5.a. Procedural focus in early perceptions of child coping

Initially, most parents described their child as concerned with "what do I have to do" (ID7, mother, *TP53*) for procedures rather than cancer risk or long-term outcomes. For many, their child's main concern was needles: "[Child's name] is literally only worried about the needle, that is the big fear" (ID5, mother, *TP53*).

However, some also acknowledged uncertainty around how their child truly felt about their cancer risk, recognizing if they did have worries, they were rarely expressed openly: "not explicitly, but I would have thought he would be anxious himself, but he did not say it in words" (ID9, father, non-*TP53*).

5.b. Growing risk awareness and emerging anxiety with increased cancer exposure

As children aged, surveillance intensified, or cancer were diagnosed, some parents described their child developing an increased awareness of their cancer risk. One parent reflected on this shift following a recent finding: "I thought he was dealing with it OK…once we met with that doctor, it all came to the forefront, poor thing. Now it's playing on his mind" (ID5, mother, *TP53*). With this growing awareness, children were described as asking more questions about their condition or expressing anxiety about what would be found in procedures.

Exposure to cancer within the family or through personal illness also shaped how some children understood and coped with surveillance. One parent whose child had recently completed cancer treatment described their child's anxiety as linked more to their condition than procedures: "I think it makes her nervous in the sense of…you have to wait for results…it's important not to confuse the

condition with the surveillance…it's the condition, not the surveillance, that causes that stress" (ID11, father, *TP53*).

5.c. Parents acting as 'emotional buffers' for their child

Some parents described managing emotional impacts of surveillance on their child by positioning themselves as 'emotional buffers'. This involved controlling how information was shared, limiting discussions about cancer risk, or downplaying their own anxieties to help maintain surveillance adherence and avoid distress or refusal: "it was a tough day for me. I contain all that and hold that and [child's name] doesn't experience any of that" (ID6, mother, *TP53*). However, one parent acknowledged this approach may also shape how their child processes stress: "she may have stress in her body but not feel upset by it. A bit like what I'm doing, but her own version" (ID6, mother, *TP53*). Parents also acted as emotional buffers in their role as decision-makers, often not presenting surveillance as a choice to their child.

Theme 6: Enduring desire to benefit child and contribute to research.

Parents described sustained motivation to participate in SMOC-Junior and regular surveillance more broadly. This was grounded in desires to benefit their child while also contributing to research to benefit others.

6.a. Benefits outweigh burdens

Most parents consistently framed participation in surveillance as psychologically challenging but necessary for their child's long-term survival: "she will get cancer…so I don't care about the psychological downfalls…I just want her to have a long life" (ID1, father, *TP53*). Clear results could also provide psychological benefits through reassurance and temporary relief.

However, not all parents perceived benefits as clear-cut. One parent acknowledged ambiguity around the value of surveillance for their child's condition: "I feel like it's not an extreme beneficial thing because I'm not even sure what the research behind of what we're going to get, for [child's condition] (ID3, mother, non-*TP53*). Despite this uncertainty, support for surveillance and the SMOC-Junior study often persisted, even following difficult experiences or cancer diagnoses: "no one should not do the SMOC study. It's given [child's name], hopefully a lot more time–time where he's well and not sick" (ID2, mother, *TP53*).

6.b. Finding meaning through contributing to research and future families

Many parents described participation in SMOC-Junior as an opportunity to contribute to research and help improve outcomes for other families. This provided meaning and purpose, reinforcing their engagement with surveillance over time: "to be able to give other families information that will help them navigate their life and have the best possibilities, that means a lot to us" (ID6, mother, child *TP53*).

4. DISCUSSION

This is the first longitudinal qualitative study to examine parents' experiences of their child's (< 18yrs) surveillance for genetic cancer risk, with a unique focus on conditions where WBMRI is indicated. Parents described surveillance as a challenging but necessary process marked by cyclical procedural and outcome-related uncertainty followed by periods of relief. These findings echo previous research in families managing genetic cancer risk(22–24), and the broader pediatric imaging literature(28, 29). While familiarity eased the process for some, others described increasing challenges over time, compounded by added external psychosocial stressors. These findings align with established stress and coping frameworks(30, 31), and informed a data-led conceptual figure illustrating the evolving nature of parental stress and coping in response to surveillance (Fig. 1). Parents' initial appraisals of cancer risk, child coping, and anticipated benefits or burdens shape whether surveillance is perceived as threatening. Coping strategies may either reduce or amplify stress, as external pressures interact with appraisals, demands, and coping to influence experiences.

Within this framework, parents described developing coping strategies to address both procedural and outcome-related uncertainty. Outcome uncertainty resulted in emotional coping that often-included avoidant strategies like emotional numbing. While these strategies may help parents cope in the short-term, they can increase vulnerability to poorer psychological outcomes over time(32, 33). Previous research has called for psychological interventions to address anxiety and avoidant coping in mothers of children with genetic cancer risk(23). In our study, both mothers and fathers described persistent cancer-related fears and engagement in avoidant coping. Given parents' central role in supporting surveillance adherence in younger children, and potential for parent coping styles to influence child coping and wellbeing(34, 35), targeted psychological interventions addressing cancer-related fears, tolerating uncertainty, and avoidant coping in parents could be explored. Embedding psychological support within surveillance care models would enable proactive delivery of such interventions(20).

Practical coping involved strategies to reduce procedural uncertainty by reclaiming control. Relationships with the clinical surveillance team were central in reducing procedural burden, functioning as a source of support and an advocate in care coordination, consistent with previous research(24, 28). However, procedural burden was shaped by multiple points across care pathways, including interactions with technical and administrative staff, where parents took on the 'expert parent' role. This placed additional responsibility on parents and contributed to sustained practical and emotional burden as they navigated a complicated and highly specialized medical landscape. Challenges associated with care-coordination have previously been reported as barriers to accessing follow-up care for genetic cancer risk in children with cancer(36), and a barrier to surveillance adherence in LFS more broadly(5). These findings suggest that promoting engagement and ongoing adherence to surveillance requires integrated, multidisciplinary care with proactive coordination, communication, and condition-specific, child-appropriate support delivered across surveillance pathways(16). Streamlined scheduling, reduced wait-times for results, and interventions to improve workforce understanding may further reduce procedural uncertainty and parent burden.

Parents' early descriptions of their child's coping focused on procedural aspects of surveillance rather than cancer fears, consistent with previous studies(22–24). While prior work has interpreted this as reflecting low child distress(23), the longitudinal design of our study suggests a more complex pattern over time. Some parents reported increased emotional distress in their child as they aged, medical interventions intensified, or cancers were diagnosed, particularly those with prior traumatic medical experiences or personal/family cancer history. Additionally, early descriptions of low distress may reflect coping processes within family contexts. Parents in our study reported suppressing fears and limiting discussions of cancer risk to protect their child, or acknowledged their child likely had unexpressed concerns. This suggests parents and children may engage in mutual emotional suppression as a form of dyadic coping(35), with children potentially withholding questions about cancer risk to avoid upsetting their parent(37, 38). This may make it more challenging to identify distress in children and has been associated with increased anxiety and lower pediatric quality of life(34, 35). These findings highlight the need for proactive and ongoing psychological screening that goes beyond surface-level, single timepoint assessments to identify emerging distress in children over time. Strategies to support parent-child communication or encourage adaptive coping could also be explored.

Strengths include the longitudinal approach and demographic and clinical diversity of families, including parents of children with and without personal cancer history. Future studies should include parents with genetic cancer risk to understand how their experiences interact with their child's care, a larger sample to enable examination of differences across conditions, and examine barriers to engagement and risk factors for surveillance non-adherence.

4.1 Conclusion

Parents in this longitudinal study generally viewed WBMRI based surveillance as worthwhile, even as they navigated persistent uncertainty, practical burdens, and fragmented care. Findings highlight the central role parents play in sustaining adherence in children with genetic cancer risk and underscore the need for streamlined care models and embedded psychosocial support to reduce distress for parents and children.

Declarations

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Author's Contributions

Conceptualization: JDH, KH, MP, NAFB, MLB, KB, CEW, KMT, DMT, DM, EKC, MW

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Ethics and informed consent

This study was conducted in line with the Declaration of Helsinki and received ethics approval (HREC:2020/ETH00592). All participants provided informed consent to participate.

Data availability

De-identified participant data may be made available on request to the corresponding author.

Competing interests

KMT has received an honorarium for preparing educational material on Von Hippel–Lindau disease and for participating in a committee to progress access to medical treatments for Von Hippel–Lindau disease in Australia. All other authors have declared no conflicts of interest.

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Tables

Tables 1 to 3 are available in the supplementary files section

Figures

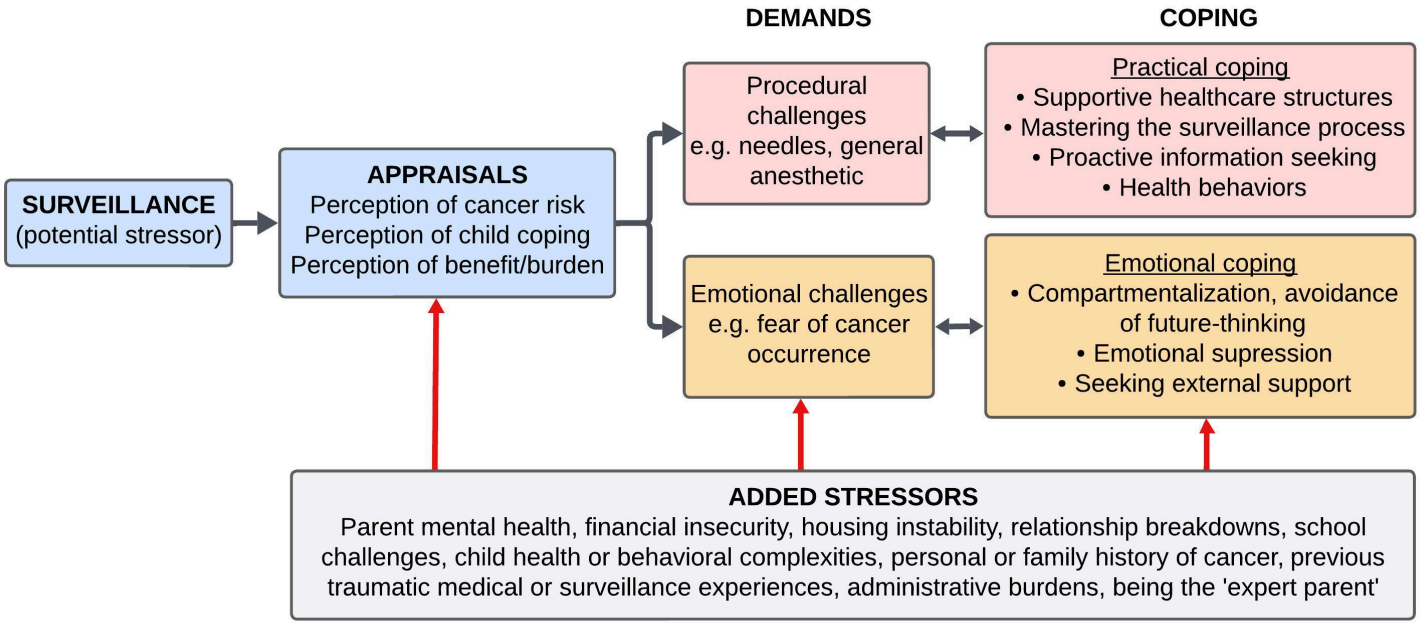


Figure 1

Longitudinal model of parental stress and coping with surveillance for their child with multi-organ genetic cancer risk. Data led figure informed by identified themes and subthemes and existing stress and coping frameworks (Lazarus 1984, Patterson, 1988).

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- Table1.docx
- Table2.docx
- Table3.docx
- Supplementarytable1.docx