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Short title:

Feasibility of an intervention for adults with cancer parenting young children.

Title:

Feasibility of *Enhancing Parenting In Cancer (EPIC*), a psycho-educational intervention for communicating with children about parental cancer.

Key Points:

- Parents with cancer have high rates of distress and their children are at increased risk of adverse psychosocial outcomes.
- A psycho-educational intervention entitled EPIC, was developed to support adults with cancer parenting young children (3-12 years) and their co-parents.
- EPIC was evaluated with parents currently receiving cancer treatment with curative intent or a view to longer-term survival, and/or their co-parents.
- Feedback suggested EPIC was acceptable, unlikely to cause distress and improved participants' confidence communicating with their children.
- Results support an RCT with larger samples, determining EPIC's potential use in routine care.

Background

Longitudinal data estimate that 1 in 353 Australian children under 12 experience parental cancer diagnosis; and this number is increasing(1). These children are at increased risk of adverse psychosocial outcomes(2), however, effective family communication about a parental cancer diagnosis may support child coping(2) especially when developmentally appropriate language is used(3). Parents report communicating with their children about their diagnosis is a major challenge and want more instructive guidance from health professionals (HPs) about meeting their children's needs(4).

Evaluation of existing interventions targeting communication and child coping suggest improvements in parental psychological morbidity, parenting competency, and child adjustment(5-8). Whilst encouraging, these interventions are typically resource intensive, involving in-person delivery(5,8). Experts note the need for sustainable(6), accessible resources including web-based programs(7).

Consequently, a psycho-educational resource entitled Enhancing Parenting in Cancer (EPIC) was created that parents could use at their convenience. EPIC comprised three components; an audio-visual resource, a question prompt list, and a follow-up phone call. During development, EPIC was evaluated by 16 oncology HPs and 12 consumers who found it acceptable for parents and co-parents(Appendix 1). A feasibility study was then conducted. This paper reports on EPIC's perceived usefulness and acceptability in a clinical sample of parents undergoing treatment while accessing the program, who participated in the evaluation of the intervention after program completion. The protocol is published elsewhere and includes details of the development of the intervention and evaluation questions(9).

Methods

Institutional ethics approval was received (Melbourne Health:HREC/16/MH/183).

Eligibility:

(a) Individuals diagnosed with cancer in the preceding 6 months or currently receiving treatment with curative intent/view to longer-term survival, parenting at least one child aged 3–12 years OR
(b) Co-parents of a): defined as another adult involved in co-parenting at least one child aged 3–12 years, AND
(c) Able to provide informed consent and participate in English
(d) Aged 18+ years.

Parents of any sex/cancer type could participate; with/without a co-parent (and vice versa). Eligibility was determined case-by-case, after discussions between the potential participant and oncologists on the study team.

Parents facing end-of-life challenges were ineligible as the language in EPIC is optimistic and reassuring about survival, and inappropriate for parents with very poor prognoses. Ineligibility was sensitively communicated and individuals were given appropriate resources.

Recruitment was planned from three Melbourne hospitals, but amended to Australia-wide following recruitment challenges(9). Recruitment was via social media and community-based cancer advocacy group newsletters.

Intervention

Audio-visual resource (AVR): this one-hour, psycho-educational chaptered tool covered; Communicating well with children; Talking about diagnosis and treatment; Talking with pre-schoolers/primary schoolers; Conversations about the future and fears of death; Maintaining family routine; and Making the most of supports(Appendices 2-3).

Question Prompt List (QPL): this suggested 19 questions to ask HPs to bridge any gaps between general AVR information and information specific to individuals, including how diagnosis, treatment or side-effects may impact parenting(Appendix 4).

Follow-up call: conducted by a psychologist to review learnings from the AVR and QPL, discuss specific issues concerning parents/partners/children, and provide referrals/additional resources on targeted topics (e.g. managing hospital visits), if required.

Procedure

After providing informed consent, participants completed the pre-intervention questionnaire (PRE-Q), then received the AVR and QPL in hard copy, or electronically. The follow-up call was two weeks post-AVR viewing. The post-intervention questionnaire (POST-Q) was completed two weeks later. Once the POST-Q was returned, an audio-recorded semi-structured evaluation interview was conducted by telephone assessing experiences, likes/dislikes, areas for improvements and whether participants had implemented intervention learnings. Data were analysed qualitatively, by repeated listening to recordings and organization of transcribed notes into related areas of concern or positive experience.

Measurements

For descriptive purposes and to inform potential future RCTs, the PRE-Q and POST-Q included measures of quality of life, family functioning, parental psychological morbidity, parenting stress, and perceptions of child adjustment(Appendix 5). Full details of these instruments are reported elsewhere(8). Clinical and sociodemographic data were collected in the PRE-Q. The POST-Q included evaluation questions about specific aspects of the intervention and participation process.

Results

Of 26 initial recruits, 17 participants(65%) completed the intervention and both questionnaires, with 15/17 completing the evaluation interview(Appendices 6-7). See Table 1 for participant characteristics. Average time from diagnosis to intervention was 5 months(*SD*=3.3,range=0-11).

Figure 1 illustrates participant feedback. Overall, most parents and co-parents agreed EPIC was helpful(92% and 80%, respectively); improved their confidence communicating with their children about cancer(83% and 80%, respectively) and supporting their child emotionally(92% and 80%, respectively); and they would recommend it(92% and 80%, respectively). Parents and co-parents agreed they felt less stressed talking with their child about cancer after

participating(74% and 80%, respectively). Many found that participation reassured them about their parenting or highlighted issues they had been unaware of (e.g., how to identify when children were not coping).

Most parents and co-parents agreed the AVR was informative(92% and 60%, respectively), easy to understand(both 100%), reassuring(92% and 100%, respectively), and relevant to their needs(75% and 60%, respectively). On interview, participants who did not agree that the AVR was relevant to their needs highlighted that the time lag between their diagnosis and the intervention was a factor and that more information on the needs of younger children would have been valuable. Most parents and co-parents disagreed the AVR was distressing to watch(92% and 80%, respectively). Most(71%) identified the AVR as the most useful intervention component and 82% considered instructive material(e.g., how to discuss diagnosis with children) the most useful AVR element.

On interview, the AVR was consistently identified as practically useful, reassuring and instructive. One person chose to view the AVR on DVD, and the other 16/17 participants(94%) opted to view it online. Participants suggested it would be most useful provided close to diagnosis and revisited once treatment commenced.

Most participants found the QPL easy to understand(88%), that it made them think about their families' needs(82%) and gave them ideas for questions to ask their doctor(65%). On interview, some participants could not accurately recall the QPL(18%). It was rated the least useful intervention component.

All co-parents and most parents (83%) found the follow-up call an important part of the intervention, stating it allowed them to speak to an expert about specific concerns and receive information tailored to their circumstances. Three participants received additional psychoeducational material or referrals for further mental health support (e.g., community child mental health services). All participants found this useful and relevant.

Discussion

EPIC was designed to support people with cancer parenting young children. This feasibility study indicated it was acceptable and well-received by parents undergoing cancer treatment, and their co-parents. Other psycho-oncology interventions have shown promising outcomes in this population(5,7). However, face-to-face delivery is problematic for this time-poor population which is difficult to engage at diagnosis or commencement of treatment(10). Additional barriers include appointment fatigue, disruption to routine, financial burden post-diagnosis, limited psychological capacity (overwhelmed) or physical inability (treatment side-effects)(11). To our knowledge, EPIC is the only parenting resource specifically designed to circumvent these challenges.

The study results illustrate the value of online resources; 94% of participants viewing the AVR online. Research involving mothers with breast cancer has identified the importance of accessible information(4). HPs have commented that accessibility increases utilisation, particularly for patients receiving substantial information at diagnosis(4). Online delivery may also facilitate intervention timing. Participants reported the intervention would be most effective soon after diagnosis, ideally before discussions with children. This was not surprising given parents received the intervention on average five months post-diagnosis, thus had told their children of their diagnosis before the intervention. This resource was designed to equip

parents for these conversations and as such, is of greatest value if accessible as soon as possible after diagnosis. If EPIC were implemented into usual care at diagnosis, parents could access the online resource when they had capacity and/or as needed. Notably, the time gap between diagnosis and intervention likely contributed to confusion about the QPL, which was designed for use shortly after diagnosis.

These data illustrate the feasibility of providing EPIC in different ways, depending on resource constraints and personal preferences. If integrated into clinical services, EPIC could be provided at diagnosis, with face-to-face/phone contact offered after parents watch the AVR. Alternatively, services with limited HP availability could use the AVR as a stand-alone resource. Notably, a strength of the AVR was online content complemented by clinical contact, allowing provision of missing information and tailoring information to family-specific circumstances, and parents to seek reassurance. Telephone contact also allows clinicians to identify child distress and make appropriate referrals. If the AVR were a stand-alone resource, providing details of local information or support services is important.

Limitations

EPIC does not target parents facing end-of-life challenges, limiting the intervention to parents with curable disease. Despite a 6-month recruitment campaign, the final sample - whilst similar in size to other parenting feasibility studies in this population(6) - was smaller than anticipated with 65% of participants being women with breast cancer. This reflects the demographics of cancers in adults of child-bearing age, high breast cancer prevalence, and difficulties recruiting parents for psycho-oncological research(1,6,7,10,11). Testing EPIC in larger, more culturally and linguistically diverse samples is recommended to ensure the generalizability of this resource. If EPIC were offered at diagnosis by the primary treatment team rather than recruiting independently of hospitals as was done in this study, this may assist with recruitment and permit a larger trial of this resource.

The AVR is available at: https://www.cancer.org.au/about-cancer/types-of-cancer/childhood-cancers/talking-to-kids-about-cancer.html

Conclusions and clinical implications

Results suggest EPIC is acceptable and feasible, providing targeted guidance for parents with cancer with younger children. Results support conducting an RCT with larger samples, testing:

- when EPIC would be most effective (e.g., close to diagnosis)
- whether it is suitable for adoption into routine care
- whether EPIC should be as integrated within clinical services or be a stand-alone intervention (AVR only) with accompanying resources.

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Data availability statement

The authors have full control of the primary data. The data that supports the findings of this study are available upon request from The Royal Women's Hospital, Centre for Women's Mental Health, The Royal Women's Hospital. EPIC: Enhancing Parenting In Cancer Dataset, 2018-2019.

References*

1.Martini A, Morris JN, Jackson HM, Ohan JL. The impact of parental cancer on preadolescent children (0-11 years) in Western Australia: a longitudinal population study. Support Care Cancer. 2019;27(4):1229-1236.

2.Osborn T. The psychosocial impact of parental cancer on children and adolescents: a systematic review. Psycho-oncology. 2007;16(2):101-26.

3.Ellis SJ, Wakefield CE, Antill G, Burns M, Patterson P. Supporting children facing a parent's cancer diagnosis: a systematic review of children's psychosocial needs and existing interventions. Eur J Cancer Care. 2017;26:e12432.

4.Sinclair M, Schofield P, Turner J, Rauch P, Wakefield C, Mann GB, et al. Maternal breast cancer and communicating with children: A qualitative exploration of what resources mothers want and what health professionals provide. Eur J Cancer Care. 2019:e13153.

5.Lewis FM, Brandt PA, Cochrane BB, Griffith KA, Grant M, Haase JE, et al. The Enhancing Connections Program: a six-state randomized clinical trial of a cancer parenting program. J Consult Clin Psychol. 2015;83(1):12-23.

6.Lewis FM, Zahlis EH, Shands ME, Griffith KA, Goldberger S, Shaft A et al. A pilot feasibility study of a group-delivered cancer parenting program: Enhancing Connections-Group. J Psychosoc Oncol. 2021;39(1):1-16.

7.Lewis FM, Griffith KA, Walker A, Lally R, Loggers ET, Zahlis EH, et al. The Enhancing Connections- telephone study: A pilot feasibility test of a cancer parenting program. Support Care Cancer 2017;25:615-623.

8.John K, Becker K, Mattejat F. Impact of family-oriented rehabilitation and prevention: an inpatient program for mothers with breast cancer and their children. Psycho-oncology. 2013;22(12):2684-92.

9.Stafford L, Sinclair M, Turner J, Newman L, Wakefield C, Krishnasamy M, et al. Study protocol for Enhancing Parenting In Cancer (EPIC): development and evaluation of a brief psycho-educational intervention to support parents with cancer who have young children. Pilot Feasibility Stud. 2017;3(1):72.

10.Stafford L, Sinclair M, Newman L, Rauch P, Barton M, Gilham L, et al. Why did we fail? Challenges recruiting parents with cancer into a psycho-educational support program. Psycho-oncology. 2019;28(12):2425-8.

11.Inhestern L, Haller AC, Wlodarczyk O, Bergelt C. Psychosocial Interventions for Families with Parental Cancer and Barriers and Facilitators to Implementation and Use - A Systematic Review. PLoS One. 2016;11(6):e0156967.

**Please see data the data availability statement (above) for the data citation reference.*

	Total (N=17)	Parent with cancer (n=12)	Co-parent (n=5)
Age			
Mean(Standard Deviation)	41(4.8)	40(4.2)	41(6.9)
Range	35-52	35-51	34-50
	N(%)	**n(%)**	**n(%)**
Sex			
Female	13(76.5%)	11(91.7%)	2(50%)
Diagnosis[†]			
Breast	11(64.7%)		
Haematological	5(29.4%)		
Skin	1(5.9%)		
Relationship status			
Married/cohabiting		10(83.3%)	5(100%)
Separated/divorced		2(16.7%)	
Employment status			
Working full/part-time		4(33.4%)	4(80%)
Home duties		1(8.3%)	
Sick leave/leave of absence		7(58.3%)	1(20%)
Education			
Tertiary		9(75.0%)	2(40%)
Trade/TAFE[‡]/Certificate		3(25.0%)	3(60%)
Number of children in family (all ages)at time of diagnosis			
1	2(14.3%)		
2	9(64.3%)		
3	3(21.4%)		
Number of children in family aged between 3 and 12 at time of diagnosis			
1	5(35.7%)		
2	7(50.0%)		
3	2(14.3%)		
Ages of all children in the family at time of diagnosis (years)			
0-2	3(10.3%)		
3-6[§]	11(37.9%)		
7-12[§]	14(48.3%)		
13-15	1(3.4%)