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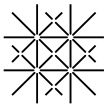
Enhancing adjustment to parental cancer: Counselling interventions for families with a parent with cancer

Inauguraldissertation zur Erlangung der Würde eines Doktors der Philosophie
vorgelegt der Fakultät für Psychologie der Universität Basel von

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aus Reinach, Schweiz

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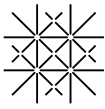
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1. ABSTRACT

The challenges of a parental cancer diagnosis not only affect the patients themselves, but the entire family. Moreover, there is evidence that family members are at increased risk of developing psychosocial problems.

Therefore, the aim of the research projects presented within this cumulative dissertation was to obtain a better insight of the impact of parental cancer on the family and to develop, implement and evaluate interventions to support families in this exceptional situation.

The first two publications cover results of the feasibility of and the lessons learned from a web-based intervention program during the first months of treatment. Furthermore, it reports on psychological adjustment in children of a parent with cancer, family satisfaction and communication, and on the effect of minimal contact interventions on the couple. Due to the low enrolment rate, feasibility of the web-based program was limited. Baseline data of the 28 participating children showed a good adjustment to the parental cancer diagnosis and high family communication levels. Couples showed signs of anxiety and decreased optimism scores at baseline, which slightly improved in patients. Feedback from participating families exhibit that the program was helpful for families with a newly diagnosed parent who are in need of specific information on cancer and family.

The third publication discusses the feasibility and acceptability of a face-to-face short-term counselling intervention. Data showed a limited feasibility but good acceptability of the counselling. It was considered recommendable and helpful by nearly all participating families. The enrolment rate was low due to different reasons, such as having no need, lack of time, or local distance.

Our research projects suggest that a parental cancer diagnosis may represent a burden, may trigger anxiety and may decrease optimism. Low-threshold interventions represent a helpful option to use at a time when needed.

2. BACKGROUND

Over the past years, there has been growing awareness and evidence of the impact of parental cancer on minor children and the family. Especially families in their child-raising period of life are confronted with multiple challenges when a parent is diagnosed with cancer (Ernst et al., 2011; Semple & McCance, 2010). A substantial proportion of cancer patients between 20 and 54 years has children (Weaver, Rowland, Alfano, & McNeel, 2010). Internationally, the number of cancer patients with minor children is estimated at 14-18% (Krauel et al., 2012; Weaver et al., 2010). In Switzerland, 13% of the cancer cases occur before the age of 50 (Bouchardy, Lutz, & Kuehni, 2011). A cancer diagnosis marks a major stressor, challenging the emotional, social, behavioural, cognitive and psychological functioning of all family members (Visser, Huizinga, Van der Graaf, Hoekstra, & Hoekstra-Weebers, 2004). Cancer patients often show elevated levels of distress during the course of the illness and the treatment, which affects family life and stability (Pitceathly & Maguire, 2003). Medical interventions, hospitalisation, changes in the physical appearance and dealing with the life-threatening situation is burdensome for the entire family. Parents of minor children are additionally challenged due to insecurities in their parenting role and concerns about the impact of the disease on the children (Inhestern & Bergelt, 2018; Romer & Bergelt, 2014). In summary, parental cancer affects the individual, the couple, and the children and initiates heterogeneous coping patterns.

2.1. Impact of parental cancer on patients and partners and marital relationship

A cancer diagnosis represents a life-threatening disease, which is associated with elevated level of distress and decreased quality of life (Ernst, Beierlein, et al., 2013; Weis & Boehncke, 2011). Regardless of parenthood, one quarter to one third of cancer patients develop clinically relevant psychological symptoms (Caruso, Nanni, Riba, Sabato, & Grassi, 2017; Hartung et al., 2017; Mitchell et al., 2011; Singer, Das-Munshi, & Braehler, 2010). Adjustment disorders, anxiety and depression are the most frequently named mental

health conditions of patients suffering from cancer (Kuhnt et al., 2016; Mitchell et al., 2011; Weis & Boehncke, 2011). Cancer patients with children show lower levels of emotional and social functioning and higher levels of distress and anxiety in the first months after the disclosure of a cancer diagnosis compared to cancer patients without children (Ares, Lebel, & Bielajew, 2014; Gotze, Ernst, Krauss, Weissflog, & Schwarz, 2007). Furthermore, stress levels are especially high in female patients with children older than 6 years (Krauß, Ernst, Kuchenbecker, Hinz, & Schwarz, 2007). In general, prevalence rates for mental disorders in cancer patients are higher than in the general population (Hartung et al., 2017; Singer et al., 2010) but decrease over time (Gazendam-Donofrio et al., 2009). Findings on gender differences in anxiety and depressive symptoms are inconsistent (Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008). Female patients show a lower quality of life and higher levels of anxiety than male patients do (Ernst, Gotze, et al., 2013; Kuenzler, Hodgkinson, Zindel, Bargetzi, & Znoj, 2011). High anxiety levels of male patients may be associated with parenthood (Akter, Khan, Khan, & Hossain, 2016; Ernst, Gotze, et al., 2013). In addition, prevalence rates for any mental disorder are highest in patients with breast, head and neck cancer and lowest in patients with pancreatic, stomach, oesophageal and prostate cancer (Mehnert et al., 2014). The manifestation of mental disorders in cancer patients is influenced by demographic characteristics (e.g. sex, age, socio-economic factors), disease factors (e.g. treatment phase, presence of pain, disease stage) and psychosocial factors (e.g. parenthood, minor children) (Ernst, Gotze, et al., 2013; Mehnert et al., 2014; Weis & Boehncke, 2011).

Usually, partners of cancer patients are the primary caregivers. Accordingly, they are exposed to numerous social, emotional and health-related problems and have to deal with many new responsibilities (Stenberg, Ruland, & Miaskowski, 2010). They are challenged with uncertainties concerning the course of the cancer, different needs of the family members, altered roles and they are expected to provide adequate emotional support for the ill partner (Baik & Adams, 2011). They have to fulfil a double role, dealing with own emotions and changing their own lifestyle due to caring for the ill partner (Kuenzler et al., 2011). Usually, partners adapt well to the cancer diagnosis of a loved one (Hagedoorn, Kreicbergs, & Appel, 2011). However, a substantial minority seems to be at higher risk of developing psychiatric symptoms and showing poorer mental health when their partner suffers from cancer (Kim et al., 2015). Studies show that in cases with a

curable disease between 20-30%, and in cases with an advanced disease between 20-50% of partners of cancer patients show elevated levels of distress and symptoms of depression and anxiety (Pitceathly & Maguire, 2003). Female partners show a decrease in quality of life, physical and mental health but they report more often of personal growth experiences than male partners (Li, Mak, & Loke, 2013; Pitceathly & Maguire, 2003). Anxiety levels in female partners are particularly high compared to the levels of the ill partner (Gotze, Braehler, et al., 2012). In general, women seem to be more distressed than men, independently of suffering from cancer themselves or of caring for the ill partner (Hagedoorn et al., 2008).

Previous research dealt with the question of who is more burdened by the cancer diagnosis, the patient or the partner. They both have higher distress, anxiety and depression levels than couples who are not facing a cancer diagnosis (Gotze, Braehler, et al., 2012; Gotze, Weissflog, et al., 2012). Coping with the physical and emotional consequences of cancer and dealing with the emotional response and coping efforts of the partner seems to challenge patient and partner likewise (Gotze et al., 2017; Hagedoorn et al., 2011). On the level of the couple, it may result in adjustment difficulties including disruption of intimacy, less cohesion, increased communication problems, less mutual support and greater marital conflict (Baider, Koch, Esacson, & Kaplan De-Nour, 1998; Walsh, Manuel, & Avis, 2005). Nevertheless, literature also reports on positive effects of a cancer diagnosis on the marital relationship, such as increased closeness (Dorval et al., 2005; Drabe, Wittmann, Zwahlen, Buchi, & Jenewein, 2013). Most of the marital relationships have sufficient resources to remain stable after a cancer diagnosis and its treatment (Taylor-Brown, Kilpatrick, Maunsell, & Dorval, 2000).

2.2. Impact of parental cancer on children and adolescents

Children predominately show emotional reactions if they learn of the parental cancer diagnosis (Huang, O'Connor, & Lee, 2014; Huizinga et al., 2011; Möller et al., 2014; Morris, Turnbull, Preen, Zajac, & Martini, 2018; Walczak, McDonald, Patterson, Dobinson, & Allison, 2018). This includes a broad spectrum of worries, fears, anger, sadness and uncertainties concerning the cancer diagnosis and its treatment (Kennedy & Lloyd-Williams, 2009; Möller et al., 2014). In the first year after the diagnosis distress is particularly high and then decreases subsequently (Huizinga et al., 2010). But, children with more initial

problems remain vulnerable also beyond this period (Visser et al., 2007). In sum, the risk of developing behavioural problems or mental disorders is higher in children of parents who suffer from cancer compared to children of parents without cancer (Thastum et al., 2009; Visser et al., 2005). Signs of internalising, externalising and emotional problems are reported in about 25-30% of children of early stage cancer patients (Morris, Martini, & Preen, 2016; Visser et al., 2005; Walczak et al., 2018). This includes elevated levels of anxiety, depression, reduced self-esteem, posttraumatic stress disorder symptoms and behavioural problems such as withdrawal, worsening of scholastic performance, attention, aggressive or conduct problems (Krattenmacher et al., 2012; Möller et al., 2014; Morris et al., 2016; Nelson & While, 2002; Shah, Armaly, & Swieter, 2017). Quality of life of minor children is rarely assessed and results are inconsistent. Recent studies found quality of life levels which are comparable to norm levels (Bultmann et al., 2014; Krattenmacher et al., 2013; Morris et al., 2018), whereas older studies reported impairments in different domains such as self-esteem (Grabiak, Bender, & Puskar, 2007; Huang et al., 2014).

There is some evidence that a parental cancer diagnosis may have positive effects, such as strengthening the relationships within the family or improvements in appreciation of life and empathy (Levesque & Maybery, 2012; Phillips & Lewis, 2015; Walczak et al., 2018). Visser and colleagues conclude that most children of parents with cancer function on an equal emotional and behavioural level or even better than their norm group peers (Visser et al., 2007). However, a substantial number of children shows particularly internalising problems and to a smaller extent externalising behaviour (Krattenmacher et al., 2012; Krauel et al., 2012; Purc-Stephenson & Lyseng, 2016). This implies that some children affected by parental cancer are more vulnerable and may develop psychosocial problems. The vulnerability seems to be moderated by children's age and gender or even by an interaction of age and gender (Visser et al., 2005). Adolescent daughters and latency-aged boys seem to be at a higher risk of developing emotional and behavioural problems (Morris et al., 2018; Thastum et al., 2009; Visser et al., 2005). On the one hand, medical parameters such as type of cancer, prognosis, duration and stage of the illness have little or no impact on children's mental health (Huizinga et al., 2011; Osborn, 2007). Only, worsening and recurrent disease seem to be associated with lower adjustment in children (Huizinga et al., 2005; Krattenmacher et al., 2012). On the other hand, the child's appraisal of the parental illness, the availability of coping strategies, parental psychological

functioning and marital satisfaction mediate the child's response to parental cancer (Huizinga et al., 2011; Morris et al., 2016). Parent's mental health, especially maternal depressive mood and decreased health-related quality of life are associated with more emotional and behavioural problems in their children (Krattenmacher et al., 2012; Visser, Huizinga, Hoekstra, van der Graaf, & Hoekstra-Weebers, 2006). Despite this, a significant number of studies reported on discrepancies between parent-proxy and child self-reports; parents tend to underestimate the impact of cancer on their children (Barak, Hen, Boniel-Nissim, & Shapira, 2008; Osborn, 2007; Visser et al., 2004).

2.3. Impact of parental cancer on parenting and family functioning

A cancer diagnosis goes along with new challenges concerning the parenting role and the parent-child relationship (Catt, Starkings, Shilling, & Fallowfield, 2017; Hasson-Ohayon & Braun, 2011). Family routines are disrupted, chores have to be rearranged and parents are less available, both emotionally and physically (Inhestern & Bergelt, 2018; Semple & McCance, 2010). Parents are challenged with maintaining routines at home while finding a balance between own and parental demands (Semple & McCance, 2010). The affected parents worry about missing out on the milestones in the life of their children, concurrently they fear about telling the children about the diagnosis due to a lack of knowledge about the disease (Semple & McCance, 2010; Semple & McCaughan, 2013). Children report on having more responsibilities (e.g. chores) which is associated with reduced leisure time (Huang et al., 2014). Still, the majority of children adapts well, especially if they manage to maintain their daily routine (Helseth & Ulfsaet, 2003). Preserving daily routines seems to be an important coping strategy and is supported by an efficient support network (Inhestern & Bergelt, 2018).

Family functioning represents an important risk or protective factor for the development of psychosocial problems in children of parents with cancer (Bultmann et al., 2014; Krattenmacher et al., 2012). An open, age-appropriate and acceptance-oriented communication and flexible problem solving seem to be associated with less emotional distress and behavioural problems in children (Krattenmacher et al., 2012; Lindqvist, Schmitt, Santalahti, Romer, & Piha, 2007). Whereas, family dysfunction (e.g. low cohesion) and low family affective involvement have an opposite effect (Huizinga, van der

Graaf, Visser, Dijkstra, & Hoekstra-Weebers, 2003; Watson et al., 2006). More effective coping in parents is related to better adjustment in children (Krattenmacher et al., 2012).

2.4. Interventions to support families affected by parental cancer

Psychosocial interventions can provide support for families with minor children after the disclosure of a parental cancer diagnosis (Niemelä, Väisänen, Marshall, Hakko, & Räsänen, 2010). Parents often seek for support when they are faced with major changes such as receiving a cancer diagnosis or cancer progression (Ernst et al., 2011). On the one hand, they need support on how to communicate with their children about the disease, on the other hand on how to react if they observe changes in their children's behaviour (Ernst, Beierlein, et al., 2013; Inhestern, Haller, Wlodarczyk, & Bergelt, 2016). Children and adolescents express the need to be informed about their parent's illness, to receive support to communicate with their parents and they wish to receive specialised support when the cancer progresses or the parent dies (Ellis, Wakefield, Antill, Burns, & Patterson, 2017). Intervention programs (e.g. support groups, counselling, psycho-education) may help parents with concerns regarding communicating in an age-appropriate way about cancer and may support them emotionally and practically in their parenting competence (Lewis et al., 2015). Children may receive support in using coping styles, talk about their feelings and overcome isolation while dealing with their parent's illness (Niemelä, Hakko, & Rasanen, 2010). Despite this knowledge, Ernst and colleagues (2013) showed in a population-based sample that about 74% of parents would seek psychosocial support, but only 9% of cancer patients made use of professional family-centred support (Ernst, Beierlein, et al., 2013). This could be explained due to a lack of counselling interventions and several known barriers in attending psycho-oncological support such as stigma and privacy concerns, geographical distance or not knowing about available services (Ernst et al., 2011; Inhestern et al., 2016).

Due to the fact, that family functioning has a substantial impact on the emotional-behavioural well-being, it is recommended to offer family interventions to counteract the detrimental impact of parental cancer on the entire family. The main stake of family interventions includes elements to improve communication within the family, as well as to develop active coping strategies and knowledge about cancer and its treatment (Semple

& McCaughan, 2013). Even if several counselling concepts for families affected by parental cancer are available, only few programs have been systematically evaluated, which is partly due to a lack of appropriate instruments to assess the impact of psychosocial well-being of children (Ellis et al., 2017; Inhestern et al., 2016; Niemelä, Hakko, et al., 2010). Nevertheless, Niemelä and colleagues (2010) as well as Inhestern and colleagues (2016) report in their reviews on the positive impact of structured family-, parent- and child-centred interventions (Inhestern et al., 2016; Niemelä, Hakko, et al., 2010). The family interventions that are carried out through individual and group sessions aim at improving communication and at promoting mutual sensitivity and understanding for each other's problems and emotions. The primary aim is to minimise family risk factors. Child- and youth-centred interventions include exchanging their worries and problems in order to develop individual coping strategies. Results suggest that the offered interventions are helpful and lead to improvements in parent-child communication and in psychological and emotional functioning of the different family members, as well as reducing family conflict (Ellis et al., 2017; Inhestern et al., 2016; Niemelä, Hakko, et al., 2010). Despite the evaluation of some support program, there is still a shortage of data on feasibility and effectiveness, particularly in relation to long-term outcomes.

2.5. Web-based intervention to support families affected by parental cancer

The web-based dissemination of interventions to treat psychological problems and disorders is a novel and interesting approach in general patient populations as well as in cancer patients. Known barriers for obtaining psycho-oncological support, such as privacy and stigma concerns, time constraints to adhere to additional appointments during office hours, and geographical distance from the providers are overcome with help of web-based interventions (Leykin et al., 2012). They have important advantages for users given their wide availability of information at any hour as well as anonymity, whereas the provider receives a time- and cost-effective tool to deliver interventions to improve psychosocial adaptation to cancer (Strecher, 2007). Thus, web-based interventions could have a potential impact both from a clinical oncology and public health perspective. Effect sizes of web-based psycho-oncological interventions with an interactive format are comparable

to those of face-to-face interventions (David, Schlenker, Prudlo, & Larbig, 2011; Trask, Paterson, Griffith, Riba, & Schwartz, 2003). A specific combination of different web-based intervention types, such as e-mail therapy or psychoeducational programs represent minimal-contact or guided self-help therapies. This specific format implies the participants' autonomous use of the web-based program combined with regular feedback by a professional (Berger & Andersson, 2009; Newman, Erickson, Przeworski, & Dzus, 2003). For example, participants work individually through educative elements to enhance coping with the current challenges via the web-based program while the therapist contacts the participant to provide a feedback and to respond to questions. So far, web-based interventions for cancer patients have been provided in couple, group and single format (Leykin et al., 2012). With web-based interventions, new possibilities are available such as individually adjusted content, language or presentation. To the best of the author's knowledge, in Switzerland there are no studies evaluating the effectiveness of web-based interventions for families affected by parental cancer.

Considering the current state of literature, it is evident that children of parents with cancer, the patients themselves and their partners are at increased risk for the development of clinically relevant mental health and behavioural problems. There is a need for family intervention in the case of parental cancer, but counselling offers for families to support adjustment are still scarce in Switzerland. Based on the previous findings, a web-based and a short-term counselling intervention for families with parental cancer have been developed and evaluated.

3. OVERVIEW OF THE RESEARCH PROJECT

Between 2013 and 2016 a web-based assessment and support team for children of families where a parent has cancer (FAMOCA) was established. With the development of a short-term counselling study in 2016, the study team concentrated and consolidated the generated results from the FAMOCA study into a clinical implementation.

In the following section, the studies will be briefly described. More extensive descriptions of the structure and the content of the two different interventions can be found in the different articles.

3.1. Methods: Web-based program FAMOCA

3.1.1. Aim

FAMOCA (**F**amily **O**nline Counselling for families with parental **c**ancer) specifically aimed to evaluate the efficacy of a web-based counselling intervention during the first months of treatment to improve child's, couple's and family's adjustment to the parental cancer diagnosis.

3.1.2. Design and Procedure

FAMOCA, a web-based program for families confronted with a parental cancer diagnosis was developed by the University Women's Hospital in cooperation with the Departments of Medical Oncology and of Psychosomatics of the University Hospital Basel, the Faculty of Psychology of the University Basel and the Child and Adolescent Psychiatry Bruderholz. The overall objective of the research project was to improve adjustment of all family members during the first months after the diagnosis by enhancing open communication, active coping strategies, relationship and parenting skills. Overall, 22 families with minor children participated in this multicentre randomised controlled intervention study. After consenting to the study, families were randomly assigned to the intervention group (IG) or the control group (CG). Families in the IG worked during four months on the different modules of the FAMOCA website and were accompanied by a trained psycho-oncologist or

psychologist in training through the completion of the program. Families in the CG received treatment as usual (written information booklets about cancer).

3.1.3. Recruitment and inclusion criteria

Information about the study was published in cancer-, health-, and family-specific magazines, websites, and online forums and sent to oncologist, nurses and psycho-oncologists. Interested families or healthcare professionals could contact the study team by an online contact schedule, mail or phone. Families were included if the following criteria were given:

- 1) parent recently diagnosed with cancer and a high probability of cure,
- 2) at least one child between 3 and 18 years living in the same household,
- 3) German speaking and writing,
- 4) basic computer skills.

Patients who did not live with their children or without custody of their children were excluded.

3.1.4. Measures

All families filled in various online questionnaires before randomization (T1), 16 weeks after randomization (T2) as well as one year after the initial cancer diagnosis (T3). General demographic and medical data were assessed by questionnaires sent via mail. Questionnaires measured parent's and child's mental health, coping and quality of life, and child-, couple-, and family adjustment to the cancer diagnosis over time (Figure 1).

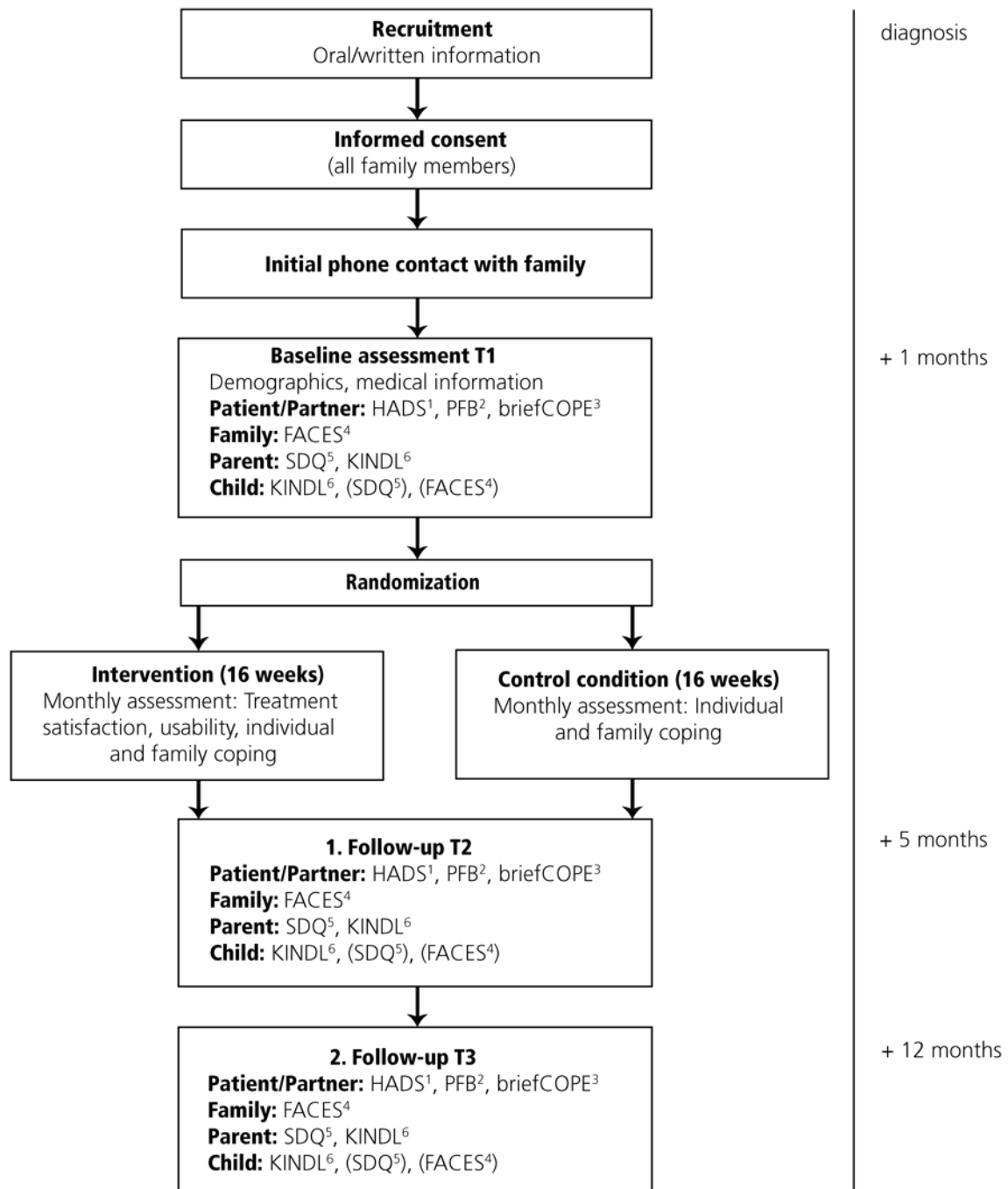


Figure 1. Study procedure of the web-based program.

Note: ¹Hospital Anxiety and Depression Scale; ²Partnership Questionnaire; ³Brief Coping Orientation to Problems Experienced; ⁴Family Adaption and Cohesion Scale; ⁵Strength and Difficulties Questionnaire; ⁶Health-related Quality of Life.

3.2. Methods: Short-term counselling for families with parental cancer

3.2.1. Aim

The short-term counselling aimed to develop, implement and evaluate a short-term intervention for families with parental cancer in the Cancer Centre of the University Hospital Basel to enhance adjustment in all family members to the parental cancer diagnosis.

3.2.2. Design and Procedure

Overall, 11 families participated in this randomised, wait-list-control study. After consenting to participation, families filled in different questionnaires and were then randomised either to the intervention group (IG) or the wait-list-control group (WG). Families in the IG participated in the counselling for a maximum of six sessions. Families in the WG started the same counselling six weeks later. A psycho-oncologist conducted the counselling.

3.2.3. Recruitment and inclusion criteria

Families received information about the study by the attending physician, the nursing staff or the psycho-oncologist. Furthermore, study flyers were sent to different external providers (e.g. cancer league, schools). The study team contacted the family by phone to give detailed information about the counselling. Families were included if the following criteria were given:

- 1) parent with a cancer diagnosis (incl. relapse, cancer stage I-III) within the last 12 months,
- 2) at least one child between 2 and 18 years living in the same household,
- 3) German speaking.

Families were excluded from the study if the diagnosis was more than one year ago or the ill parent did not live with the children or had no custody of the children.

3.2.4. Measures

Families received questionnaires on family, parental and individual psychosocial functioning before the counselling (T1), after the counselling (T2) and six weeks after the completion of the counselling (T3). Sociodemographic and medical information were obtained from parents and the treating physician. Children younger than 11 rated their quality of

life, whereas adolescents (>12 years) filled in questionnaires about their quality of life, emotional-behavioural functioning and overall family functioning. Parents appraised behavioural problems, social competencies and quality of life of the children and filled in questionnaires about their mental health, relationship satisfaction and overall family functioning (Figure 2).

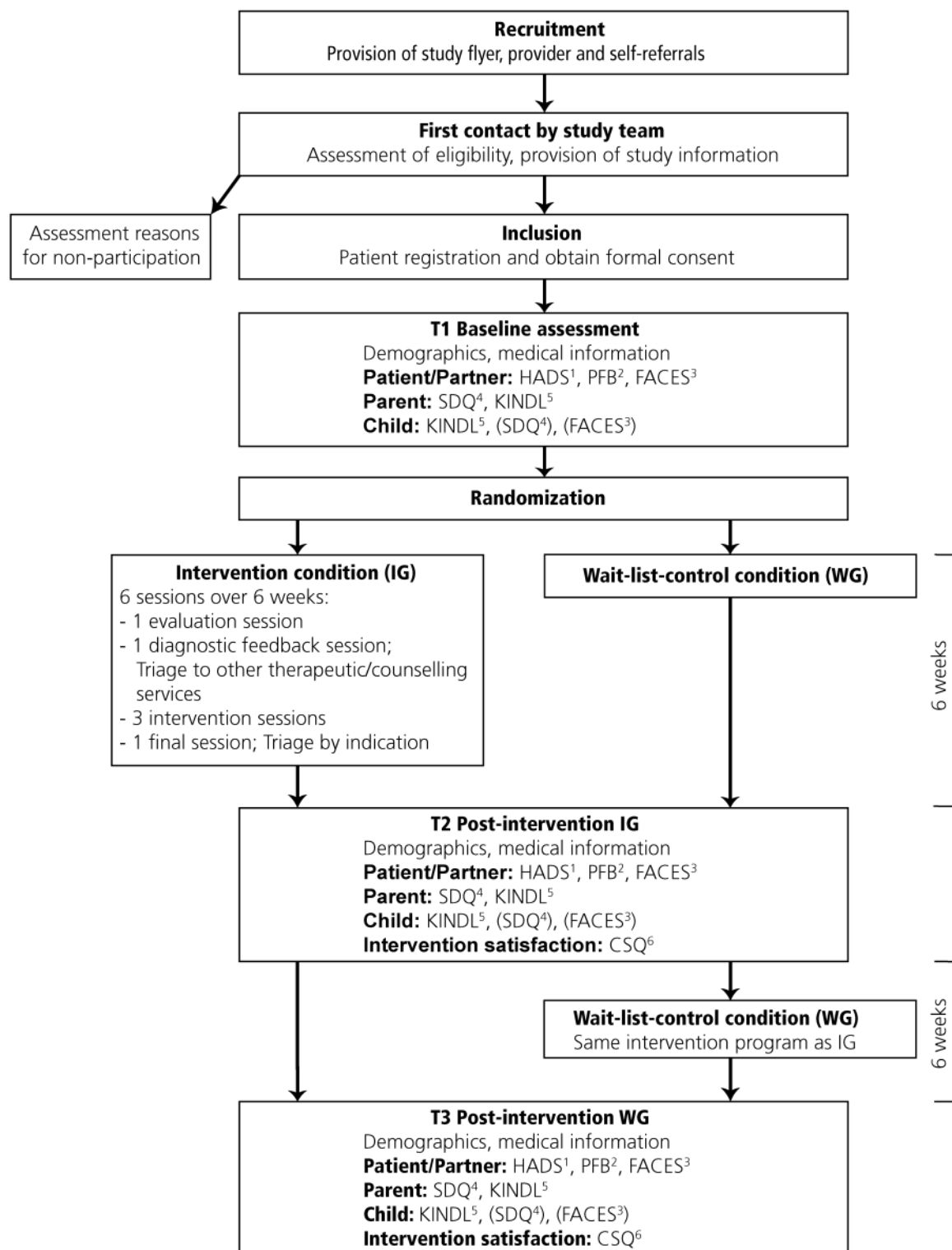


Figure 2. Study procedure of the short-term counselling for families with parental cancer. Note: ¹Hospital Anxiety and Depression Scale; ²Partnership Questionnaire; ³Family Adaptation and Cohesion Scale; ⁴Strength and Difficulties Questionnaire; ⁵Health-related Quality of Life; ⁶Client Satisfaction Questionnaire.

4. SUMMARY OF RESULTS

The following pages contain a short overview of the main results of each article. Article 2 and 3 are submitted to peer-reviewed journals, whereas Article 1 was published. All articles are listed in the appendix, where further information on methods and detailed descriptions of the results may be found.

Publication 1

Web-based counselling for families with parental cancer: Baseline findings and lessons learned (Denzinger, et al., 2019)

This article describes the baseline results of overall family functioning and quality of life and emotional-behavioural well-being of children with a parent recently diagnosed with cancer. Furthermore, the article discussed the lessons learned and the use and satisfaction with the FAMOCA program. Results showed a good adjustment to the parental cancer diagnosis with no clinically relevant levels of emotional and behavioural problems and normal level of quality of life in children. Parents tended to rate their children's behavioural-emotional difficulties and quality of life levels lower than their children did. Family satisfaction levels were rated as low, whereas family communication as high. Families rated the impact of the FAMOCA program on the adjustment process as moderate. In general, FAMOCA seemed to help especially families with a newly diagnosed parent. They needed a low-threshold support and specific information on cancer and family rather than intensive psycho-oncological care.

Publication 2

Feasibility of minimal contact interventions is limited in couples affected by a new cancer diagnosis (Bingisser, et al., submitted)

This article also provides results from the FAMOCA study aiming at assessing the psychological adjustment of couples participating in minimal contact interventions. Main findings

included a low enrolment rate and full adherence to the interventions in 50% of all patients. The reasons given for drop-out were time issues and lack of interest. At diagnosis, patients and partners showed elevated anxiety levels, which decreased at 16 weeks follow-up. Further results showed no significant changes in quality of marital relationship, coping styles, depression and pessimism scores. Optimism scores were slightly decreased in patients and partners at inclusion and significantly increased in patients 16 weeks follow-up. Furthermore, this article discussed reasons for the limited feasibility of minimal contact interventions. Even though, the beneficial effects of minimal contact interventions in couples remained unclear due to the low enrolment rate, the authors concluded that minimal contact interventions for families affected by parental cancer may have a place in the future, particularly in the early phase of cancer treatment.

Publication 3

Feasibility and acceptability of a short-term counselling intervention for families with parental cancer (Denzinger, et al., submitted)

This article reports on the feasibility and acceptability of a short-term counselling for families with parental cancer. Of 142 potentially eligible families, 71 (50%) were within the decision process, 60 (42.3%) declined to participate and eleven (7.7%) were included. Reasons for non-participation were having no need (43.3%), being already referred to other psychosocial services (20%), not being fluent in German (16.7%), lack of time due to many medical appointments (10%), no reason (5%), local distance (3.3%), and severity of illness (1.7%). Participating parents and adolescents were generally satisfied with the counselling and the different sessions. About 75% of participants would recommend the counselling to others and all parents indicated that the counselling met most or almost all of their needs. Whereas attrition was low and satisfaction with the counselling high, the enrolment rate remained low. Potential reasons and solutions for the low enrolment rate and limitations of the counselling were discussed. Overall, the short-term counselling was appreciated by families affected by parental cancer, as an option to use at a time needed.

5. DISCUSSION

Psycho-oncological family-centred counselling programs have been shown to elevate parents' and children's well-being after one parent received a cancer diagnosis. However, there is still a paucity of family-focused health services in Switzerland. Therefore, the aim of the two research projects was to implement and evaluate two different counselling interventions at the Cancer Centre of the University Hospital Basel to enhance family adjustment to the parental cancer diagnosis. The research in this dissertation provides insight in the well-being of children and parents after one parent was diagnosed with cancer, as well as in the implementation of two interventions trying to support families in this unique situation. In the following, the results will be discussed separately per project.

5.1. The FAMOCA program

The results of the first article showed that children and adolescents adjusted well to the parental cancer diagnosis. Levels of emotional-behavioural problems and levels of quality of life were comparable to levels of a norm population. Parents ratings of their children's problems and quality of life and children's self-report were comparable and only differed significantly in family related quality of life ratings. Parents rated family related quality of life in their children lower than their children themselves did. Results on family functioning showed high levels in family communication and low levels in family satisfaction. Furthermore, article 1 dealt with the evaluation of benefits and drawbacks of working with the FAMOCA program. The program was appreciated, in particular the interactive parts. However, enrolment was low and attrition from the study high.

The main finding in article 2 included a limited feasibility of minimal contact interventions in newly diagnosed cancer patients due to the already mentioned low enrolment rate and high attrition rate in the FAMOCA study. In addition, couples' anxiety, depression, optimism, pessimism and quality of relationship levels were assessed and compared before and after participating in a minimal contact intervention. Anxiety levels of patients and partners were above cut-off scores at baseline and decreased significantly in patients

during the first months of therapy, whereas optimism scores were subdued in patients and partners and increased significantly in patients.

Taken together, parents, children and adolescents who participated in the FAMOCA study showed normal levels in mental health, quality of life and family functioning measures at baseline. This is in line with previous research, showing a normal adjustment process in about 70% of children and parents who are confronted with parental cancer (Osborn, 2007; Pitceathly & Maguire, 2003; Singer et al., 2010; Visser et al., 2004). In correspondence with previous literature, increased anxiety levels and decreased optimism levels both in patients and partners show that a cancer diagnosis affects not only the patient but also the couple (Hagedoorn et al., 2011). In previous studies, parents tend to report fewer behavioural-emotional problems and lower quality of life scores in their children than their children report (Osborn, 2007; Robitail et al., 2007; Visser et al., 2004). These results are comparable to our findings of discrepancies between parent-proxy and child self-reports. It seems that parents underestimate the impact of parental cancer on the child, in particular in the field of behavioural-emotional well-being (Inhestern, Geertz, Schulz-Kindermann, & Bergelt, 2018; Morris et al., 2016). Even though literature reports on high distress levels, especially in latency-aged boys and adolescent girls, parents might think that their child is doing fine (Thastum et al., 2009; Visser et al., 2005). On the one hand, especially young adults seem to be good at hiding their emotions and at staying functional while managing daily and school-related tasks as well as supporting their parents (Inhestern et al., 2018). On the other hand, comparable to our results, literature reports on high anxiety levels in female patients (Ernst, Gotze, et al., 2013; Kuenzler et al., 2011). High mental burden may decrease parent's attention to the mental state of their child. Parents might be less emotionally available and thus less attentive towards the full extent of their child's suffering (Inhestern et al., 2018; Lewis et al., 2015). Parent's poor mental health is a risk factor for the development of children's emotional-behavioural problems (Krattenmacher et al., 2012; Visser et al., 2006). These families could benefit from an additional support program to prevent the development of mental health problems. Increasing parent's awareness of possible consequences of the cancer diagnosis on themselves and on the emotional adjustment of their child and underlining the preventive character of such support offers, may help in overcoming parents' personal barriers to seek additional psychosocial support (Inhestern et al., 2016).

The fact, that the majority of the participating family members showed a good adjustment to the parental cancer diagnosis may to some extent explain the high attrition rate suggesting that there was no need for further support. Resources of families in this unique situation are limited and family time is restricted. Family feedback on the FAMOCA program showed that families often dropped out due to time constraints, preferring activities unrelated to the parent's cancer to working on the program. Participating in a study next to maintaining daily routines and treatment demands may represent rather an additional strain than a relief. This is confirmed by Kuehne and colleagues, who reported that patients sometimes seem so preoccupied with their disease that they seem not to have any resources left for other appointments (Kuehne et al., 2013). Although web-based interventions reduce common barriers (e.g. time constraints, geographical distance from the provider), the wish to spend time with the family seems to be stronger (Leykin et al., 2012). Spending time with their family helps parents to regain strength and enhances family cohesion (Inhestern & Bergelt, 2018). In addition, the content of the FAMOCA program might not have fully satisfied the expectations of the participating families. Adolescents preferred other sources of information and some parents criticised that the provided information was already known and there was too much text to read. Especially persuasive technology (e.g. tailoring, tunnelling) seem to improve retention rate (Kelders, Kok, Ossebaard, & Van Gemert-Pijnen, 2012). Participants confirmed that they are more motivated to follow short and concise recommendations than to extract the important pieces of information from a written text. However, almost all families appreciated recurrent monthly phone contact. Counsellor support and email or phone contacts are considered as intervention characteristics that enhance adherence to web-based interventions (Brouwer et al., 2011; Kelders et al., 2012).

Support offers are often sought out if the parents perceive a need for their children or other family members and especially if any behavioural changes become apparent in their children (Inhestern et al., 2018; John, Becker, & Matthejat, 2010; Semple & McCaughan, 2013). This seemed not to be the case in our study and could have affected the enrolment rate. Additionally, FAMOCA only included families within the first months of cancer therapy. Difficulties and distress can vary over the course of cancer therapy, making it difficult to determine at which stage families would benefit the most from an additional psychosocial support offer. While FAMOCA specifically aimed at supporting

families with a newly diagnosed parent, literature shows that interest in participating in a support intervention is low in this patient group (Romer et al., 2007; Shah et al., 2017). In our study face-to-face recruitment was more powerful than passive online recruitment. Therefore, health care professionals and the attending physician should be trained in detecting families at need, because support offers are more readily accepted when recommended by a health care professional (Romer et al., 2007; Shah et al., 2017). Online recruitment might work better in following generations due to higher habituation to Internet technology. Overall, non-adherence in web-based interventions seems to be an issue and can be improved by specific characteristics, such as increased frequency of interaction with a counsellor (Kelders et al., 2012).

In summary, the web-based minimal contact intervention FAMOCA seems not to be suitable for the acute situation after diagnosis as is shown by rather poor attendance of families. It seems that despite the increasing digitalised world, the personal contact is particularly needed in times of crisis, whereas an online support might be supplementary through the cancer therapy and afterwards. Online counselling is able to generate initial contacts and to lower inhibitions and therefore might be most useful as temporary supportive treatment and to support transition to outpatient face-to-face counselling services (David et al., 2011). The limited feasibility, low enrolment rate of the web-based intervention, the wish of participants for more face-to-face contact and the still existing dearth of counselling interventions for families with parental cancer in Switzerland led to the decision to develop the outpatient short-term counselling for families with parental cancer.

5.2. The short-term counselling for families with parental cancer

The main findings of article 3 exhibit a good acceptability of the short-term counselling and its content. The counselling met almost all of the families' needs and they would recommend it to others or would participate again. Families appreciated the low-threshold treatment and having a person to contact for future concerns about their children. The main reason for parents to participate in the counselling was insecurity whether their children's reaction to the parental cancer diagnosis was normal (or not). This is consistent with previous research, where parents report on difficulties to inform their children while having a lack of confidence and skills to communicate about this issue (Semple &

McCance, 2010). The majority of parents wish to receive information and support regarding how to tell the children or information on children's emotional reaction (Ernst, Beierlein, et al., 2013). Additionally, parents wish professional support to keep the balance between informing the child age-appropriately and protecting it from the uncertainties established with the cancer diagnosis (Helseth & Ulfsaet, 2005; Semple & McCaughan, 2013). Well-informed children adjust better to a parental cancer diagnosis than children with unmet informational need (Huizinga et al., 2003). Our counselling helped parents overcome these concerns and insecurities. The feedback of the assessed quality of life levels and behavioural-emotional functioning through parent-proxy and child self-report questionnaires revealed that many parents evaluated their children's well-being comparably to the children's own ratings of their well-being. It was reassuring for the parents not to find any discrepancies between their ratings and their children's ratings of well-being.

Retention from the study was high, but enrolment was low ending in a response rate of 18.3%. One repeatedly mentioned reason for declining participation was having no need. This was further specified by: the children are doing fine, patients are too busy with treatment demands, other topics than cancer are more present or the children are too young and parents do not want to burden them. Less frequently mentioned reasons for non-participation included not being fluent in German, lack of time due to many medical appointments, being already referred to other psychosocial services or local distance. Reasons for non-participation listed in our study are comparable to reasons mentioned in other research, such as living too far away, having little time or prevention of emotional overload (Inhestern et al., 2016; Schmitt et al., 2007). These practical and emotional difficulties for families are known to hamper willingness to use psychosocial support. Add up to the explanation why families declined to participate could be that about 60% of patients who did not want to participate in our study were already having psychological support or had at least one meeting with a psycho-oncologist. These patients might already have received the information and the reassurance they needed. In existing literature, the most frequent reason for declining participation in family-centred support included that patients felt sufficiently supported and had no need for further support (Ernst, Beierlein, et al., 2013; Inhestern et al., 2016). Like in other studies, contacted families appreciated the offer of family-centred support, but indicated that they would not need it personally (Romer et al., 2007). Whereas 73% of patients with children wish to receive

information about psychosocial services to support their children or to receive help in parenting, only about 44% use psychosocial support and 9% use family-centred support (Ernst, Beierlein, et al., 2013). Family-centred support is rather used if the child seems distressed, if the child is younger, if the family has more than one child, if the patient is a single parent or has poorer mental health (Ernst, Beierlein, et al., 2013; Inhestern et al., 2018).

Overall, when approaching families, it is important to consider disease and family variables (Kuehne et al., 2013). Treatment side effects or progress of disease, as well as treatment phase (e.g. short after diagnosis, post-treatment) may complicate taking part in a counselling intervention (Inhestern et al., 2016; Romer et al., 2007). Fear of stigmatisation due to the need of mental health services, prioritising medical procedures or the wish to protect the family from emotional overload may impede with the need for psychosocial support (Inhestern et al., 2016; Kuehne et al., 2013). Furthermore, the first contact was usually with the patient. It is known that many cancer patients have a desire for normalcy and tend to refuse psychological offers (Neumann et al., 2010). We tried to overcome this barrier by contacting the patient and the family at a later time. However, it was equally challenging to win the whole family for a study. Often participation was declined if at least one family member was against it. In our study, families rather take part in the counselling if the attending physician or psycho-oncologist recommended it. Other reasons for complicating the enrolment of families affected by parental cancer into a psychosocial counselling service are related to the care system (e.g. lack of information transfer, problems with referral of patients, perceived competition) and physician's concerns (e.g. physician's resources, well-being of patient) (Kuehne et al., 2013). Especially clinicians play an important role in giving information about additional support to cancer patients (Gallina et al., 2015). Despite the lack of sufficient information about additional services, many physicians refer their patients to psychological support only in acute situations (Neumann et al., 2010). The lack of awareness of physicians about the counselling might have led to a lack of provider referrals which influenced the enrolment rate.

5.3. Strengths and Limitations

In Switzerland, FAMOCA is the first web-based intervention including all family members affected by a parental cancer diagnosis. Minimal contact interventions have advantages for the participating families, such as independence from time and place, convenience and anonymity. For the provider it is a time- and cost effective tool to support families in this exceptional situation. The short-term counselling offers professional psychosocial and child-related support. One strength is the flexibility of the counselling towards disease and treatment changes. Furthermore, it meets the specific needs and wishes of the different family members. One of the strengths of both research projects is the low threshold of the interventions, which helps to reduce the fear of being stigmatised and may operate as a door opener for adequate psychosocial services outside the hospital. FAMOCA and the short-term counselling represent an important contribution in the highly sensitive and under-researched field of cancer and family.

There are some limitations concerning both research projects, which need to be considered and taken into account for further research. First, the findings are based on small samples of 22 and eleven families, respectively, and therefore have to be interpreted with caution. Statistical analyses were on an exploratory basis and have mainly been presented descriptively. Because of the small sample size, the statistical power was not adequate to detect statistically significant effects.

Another limitation was the unbalanced distribution of gender in cancer patients and type of cancer. Almost all patients were female and the majority suffered from breast cancer. The higher percentage of women is in accordance with previous research (Huizinga et al., 2011; Moyer, Sohl, Knapp-Oliver, & Schneider, 2009). Further research with a more balanced distribution of gender in patients and partners should investigate possible gender differences. Therefore, strategies to reach more male patients are needed and should be worked out in future. Besides the uneven gender and cancer type distribution, other variable might have led to a possible selection bias, which limits generalisability. Participating families were predominantly highly educated and of high socioeconomic status, married, German speaking, and of Caucasian origin, respectively. Therefore, the results have to be considered as specific to the described sample.

Both projects aimed to support families of cancer patients who receive curative cancer treatment. The content is not suitable for families with a parent with limited life

expectancy nor is it suitable for single parents. Single-parenthood and palliative disease are mentioned as risk factor for the development of mental health conditions, especially internalising symptoms in children of a parent with cancer (Kuehne et al., 2012; Weitoft, Hjern, Haglund, & Rosén, 2003). The short-term counselling was a single-centre study which was conducted in the tumour centres of the University Hospital Basel. Generalisability to other settings than acute care is limited.

Quality of life in children under 12 years was only rated through parent proxy reports. Therefore, ratings are insufficient for a statement about the effective quality of life of the child because parents may have failed to detect specific problems in their children and may have been influenced by social desirability bias. Rater-dependent discrepancies are known and in general, self-reports in combination with objective data are recommended.

5.4. Clinical implications and future research

The low enrolment rate of both research projects questions the feasibility of the interventions and points to difficulties in engaging families affected by parental cancer in psychosocial support programs. Despite the high number of cancer patients with minor children, there are a few evidence based psychosocial support programs to help families to manage the emotional burden of the cancer experience (Ellis et al., 2017; Inhestern et al., 2016). More intervention research is needed to promote appropriate psychosocial care for families affected by parental cancer. Children, adolescents and parents in this specific situation have different needs and health care professionals have to develop a variety of support techniques. Unfortunately, health care professionals and physicians seem to struggle to detect families who are in need of psychological counselling (Schmitt et al., 2007). The attending physician represents one of the most important sources in recruiting families for counselling interventions. In this exceptional position, he or she is a trustworthy person to lean on and hence has a key role in reaching families (Inhestern et al., 2016; Romer et al., 2007). Therefore, the awareness about the potential difficulties for minor children (e.g. developing mental health issues) in families with a parental cancer diagnosis has to be increased in oncology professionals. Article 3 showed that the number and age of patient's children are not systematically assessed, implying that the burden of a cancer diagnosis on all family members is not being sufficiently acknowledged. Comparable to

our situation, Romer and colleagues (2007) report that in their oncology clinic, it was even unknown if the patients had any children or not (Romer et al., 2007). As a solution, a questionnaire was introduced asking about the family situation and the presence of children (Romer et al., 2007). In order to recognise the children's need for help, we need to know about the family life, the mental state of the parents and the coping behaviour of the children. This could help to differ between families with a higher risk for poor adjustment and families which have good enough coping strategies. In addition, the psychosocial burden for parents is sometimes immense and they do not have enough resources to express a need for psychological support (Inhestern et al., 2018; Visser et al., 2007). Hence, child-related concerns might not be perceived as first priority. A screening tool, such as the Parenting Concerns Questionnaire (PCQ) could ease the process to detect signs of psychological distress and parenting concerns (Muriel et al., 2012). Additionally, asking about existing and applied resources and not only about distress and burden, might help to identify families in need (Inhestern & Bergelt, 2018). Furthermore, oncology professionals must be provided with information on appropriate support offers and they have to be convinced about the benefits of the specific support offer. The physician needs practical evidence of the value of the support offer which should be compatible with his personal and professional values (Kuehne et al., 2013; Romer et al., 2007). If the physician has any concerns about the supportive measures (e.g. counselling could be disturbing for patient) he is unlikely to recommend it (Kuehne, et al., 2013; Romer, et al., 2007).

Not all families require support, because a parental cancer diagnosis does not represent a major stress factor for all children. Hence, there is no need to provide psychological care for every child. Future studies should focus on identifying the subgroups of families who need psychological support or are at a greater risk of poor adjustment; families who exhibit multiple risk factors such as low socio-economic status, high pre-existing psychosocial burden or single-parenthood (Visser et al., 2004; Watson et al., 2006). These families might be more distressed and might not have the personal resources to search for psychological support. A low-threshold counselling included in the routine care with one session for every family could overcome these barriers. If the counselling is portrayed as something additional but standard to the usual treatment, it might also reduce the fear of being stigmatised as mentally ill. If a first contact exists and the counselling session was

perceived as helpful for the family, the threshold is lowered to ask for further support in the future.

Along with identifying characteristics of at risk families, future research has to focus on determining at which point in the course of the cancer treatment or of survivorship it is most appropriate to initiate an intervention. Previous studies report controversial results (Inhestern et al., 2016; Romer et al., 2007). Every family adjusts in their own time and difficulties often occur in time of crisis, which is not necessarily shortly after the disclosure of a cancer diagnosis. Furthermore, the development and testing of future interventions for families affected by parental cancer should deal with the different needs of each family member. Especially in children psychological, social and biological issues differ according to their developmental stage. Hence, the needs of families with adolescents are likely to differ from the needs of families with younger children. For example, a peer-group intervention might be more appropriate for adolescents dealing with parental cancer. Depending on the extent and nature to which the parent is experiencing the long-term and late effects of cancer or on the family structure, the needs might vary (Weaver et al., 2010). The services should be extended to include single-parents, patchwork families or parents with limited life expectancy. The structure of the intervention seems to be an important parameter for families. Support services are more likely to be used if the intervention is closely adapted to the needs and living situation of the families (Inhestern et al., 2016).

FAMOCA and the short-term counselling for families with parental cancer helped participating families and represented an option to use in the time needed. The activated resources and the enhancement of useful coping strategies might have helped the participating families to adapt well to the situation and to prevent adverse emotional consequences in their children. These two research projects are in line with the Swiss National Cancer Program (2011-2017) which aims at fighting the insufficient availability of professional psycho-oncological support and lack of family-centred interventions. One aim of the program is the elaboration of standards and guidelines for psychosocial care for cancer patients and their family members.

According to the participants' feedback concerning improvement of the FAMOCA program, all modules are now publicly and simultaneously accessible. Thus, families now have the possibility to decide freely which of the chapters of the different modules would apply to them. Furthermore, the text was shortened and currently includes short and concise

recommendations. The short-term counselling for families with parental cancer is ongoing and an evaluation of the efficacy of the counselling is needed before implementing it into standard clinical practice.

6. REFERENCES

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7. PUBLICATIONS

7.1. Web-based counselling for families with parental cancer: Baseline findings and lessons learned



Web-based counseling for families with parental cancer: Baseline findings and lessons learned

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ABSTRACT

Purpose: This is the first study in Switzerland to report on psychological adjustment in children of a parent with cancer using a web-based intervention during cancer therapy.

Design/Sample: Twenty-two families participated in this randomized controlled web-based intervention program.

Methods: Quality of life and emotional-behavioral well-being of children were examined using child self-reports, and parent proxy-reports. Furthermore, family communication and satisfaction and feedback on the web-based program were assessed.

Findings: Children's first stage adjustment to parental cancer did not show detrimental patterns. The "lesson learned" in this setting emphasizes the challenge to reach families in need. The web-based program was appreciated as an additional source of information and support in this mostly highly functioning population.

Conclusion: While feasibility was shown, it remains unclear how to contact families with lower psychosocial functioning.

KEYWORDS

child adjustment; family functioning; lessons learned; oncology; parental cancer; web-based intervention study

Background

In Switzerland, approximately 23,000 men and 19,000 women are newly diagnosed with cancer every year.¹ About 13% of them are diagnosed before the age of 50, a life stage at which having and raising children is normal and common.^{2,3} Long-term treatments and the emotional burden of a cancer diagnosis may therefore interfere with parental tasks and responsibilities challenging the entire family system.⁴

Over time, research has broadened its focus on examining the impact of parental cancer not only on the patient, but also on the entire family

system.^{5,6} Significant levels of distress and mental health problems, including depression, anxiety, and adjustment disorders occur in 32–38% of affected patients and their partners.^{7–9} For the children, parental cancer represents a highly stressful situation. Studies have shown that in 25–30% the children of early stage cancer patients show signs of internalizing, externalizing, and emotional difficulties including anxiety and mood disorders, psychosomatic problems, aggressive behavior, feelings of guilt and shame, and worsening of academic performance.^{10,11} Furthermore, a parental cancer diagnosis comes along with changes in daily routine and role functioning.^{10,12} The child's adjustment to parental cancer is moderated by his or her developmental stage, gender, and support network.¹³ Adolescent daughters and latency-aged sons report higher levels of psychosocial symptoms than adolescent boys and latency-aged daughters.^{10,13–16} In addition, parental psychological functioning, marital satisfaction, parenting skills, family functioning, and communication and coping strategies mediate adjustment to parental cancer, while medical parameters have little impact on the child's well-being.^{10,11,15,17–19}

Taken together, a cancer diagnosis poses high demands on the family system and triggers an adjustment process for the family, the couple and the individual, which may be challenging especially for families with low resources and preexisting psychosocial and health problems. For those, psychosocial support and specific interventions are needed to improve functionality of the coping process.^{20,21} Inhestern et al. summarized several parent-, child-, and a few family-centered interventions and concluded that most of them led to improvements of the quality of life (QoL) of parents and children, of depression scores, and of various aspects of family functioning (e.g. family communication).⁵ Literature shows that support is often sought out if the parents perceive a need for their children or other family members, and especially if any behavioral changes become apparent in their children.^{22,23} Furthermore, Romer et al. emphasized that families may make use of counseling following their attending physician's recommendations, because he or she represents a reliable and trustworthy person.²¹ This observation is confirmed by the review of Inhestern et al., showing that the most promising way to reach families is when the support is recommended by health care teams.⁵

The reported interventions were realized as face-to-face programs; however, in recent years, web-based interventions have started to be assessed more systematically.²⁴ As cancer patients, relatives, and adolescents commonly use the Internet as a source of information and for support,²⁵ web-based intervention programs have increasingly been shown to be valuable because of the convenience, availability, and accessibility of information at all times, as well as for reasons of anonymity.²⁶ Consequently,

web-based interventions seem to be able to overcome some of the known barriers of seeking psycho-oncological support.^{5,21}

So far, single, couple, and group web-based interventions have been described, while there is still a paucity of scientifically evaluated psychosocial interventions for entire families affected by parental cancer.^{3,23,27} Therefore, we developed and evaluated a web-based intervention program for families with a parent diagnosed with cancer. This study (1) reports on self- and parental-reported children's QoL, behavioral-emotional well-being, and family functioning at baseline and (2) discusses the usability of and the participants' satisfaction with the program as well as the lessons learned from establishing and conducting the study.

Methods

Study design

FAMOCA—*family online counseling for families with parental cancer* was designed as a randomized controlled intervention study. Developed by an interdisciplinary team of adult and child psychologists and oncologists, the study aimed at evaluating the effectiveness of a web-based, interactive, and multimedia-based intervention for families with parental cancer. The primary goal was the improvement of child and parental adjustment and family functioning. The intervention group was compared with a control group, which received treatment as usual, consisting of selected, publicly available information brochures on parental cancer for parents and children. The study protocol was approved by the local ethics committee and was registered on drks.de (DRKS00006298).

Participants and procedure

Families were eligible if a parent was diagnosed with cancer for the first time with a high probability of cure, or in the case of metastatic disease with an expected progression-free interval of 12 months. Affected parents had to have at least one child between 3 and 18 years. All family members had to be German speaking and had to have access to the Internet.

Swiss hospitals and cancer centers, physicians, and psycho-oncologists were invited to inform patients about the study after disclosing cancer diagnosis. In addition, families were recruited online by providing study information on cancer-specific websites. Interested families contacted the study team by phone or mail. In a first telephone contact, comprehensive information on the study was given and inclusion criteria were assessed. Written informed consent was obtained individually by each family member. Before randomization (T1), participants completed an online

questionnaire, including validated instruments on psychological well-being and familial coping and demographic and cancer specific questions. Five (T2) and 12 months (T3) after study inclusion, the same questionnaires were re-assessed.

Family online counseling intervention

The web-based intervention program was based on the “minimal contact” concept, which implies the participants’ autonomous use of the program combined with regular feedback by a professional.^{28,29} While participants work individually through educational elements to enhance coping with the current challenges via the web-based program, the therapist contact includes providing a feedback to the participant, responding to questions and unlocking the next module. The program was based on cognitive-behavioral techniques to foster adaption and to build up coping strategies for the entire family.

The online intervention program www.famoca.ch provided individual support for each family member by age-specific platforms for children (3–11 years), adolescents (12–18 years), and adults. While most parts of the different modules were designed for parents to work with their younger children (3–11 years), some elements, such as listening to the story and coloring the pictures were designed for the children to undertake on their own. Every 4 weeks, a new module was activated with the same age-related content for parents, adolescents, and children. For example, for children each module included listening to or reading a story of a family with an ill father, handicraft instructions, or a diary to write or draw in. Adolescents watched an educational film clip with cancer information or could use a private blog to process their experience. The content of the modules was adjusted specifically to the first period after diagnosis. A trained psycho-oncologist accompanied every family through completion of the program.

The Website consisted of four modules:

Module 1: “Understanding what’s going on”: Families were provided with educational material about communication, coping skills and strategies, and information about different cancer treatments and its consequences.

Module 2: “Dealing with everyday family life”: This module provided information on the changes in daily life and recommendations on how to maintain family functioning.

Module 3: “Caring for myself and each other”: This module assisted families in dealing with emotions aiming to foster parental competences regarding emotional responses in children as well as to enhance emotional interaction within the couple and the family.

Module 4: “Planning the future, integrating the past”: This module offered the opportunity to the family to reflect on the changes and the possible

progress over the last 4 months. It helped to integrate new coping behaviors and to identify the resources of each family member to maintain open communication and mutual support.

A detailed description of the program may be found in the publication of Bingisser et al.³⁰

Study measures

Children's QoL

The QoL of children was measured by the generic KINDL-R questionnaire.³¹ It includes self-report forms for children aged 3–6 years and 7–17 years and for each age group a corresponding parent-version. The self-report form for age 3–6 years includes only 12 items resulting in one overall well-being score, which can be compared with parents' reports. It provides good internal consistency (Cronbach's alpha = 0.80).³¹

Children's behavioral–emotional adjustment

Children's behavioral–emotional adjustment was measured by the German version of the Strengths and Difficulties Questionnaire (SDQ),³² a child- and parent-reported brief screening questionnaire for children between 2 and 18 years. Adolescents between 12 and 18 years filled in self-ratings. The total score includes results from all subscales except for the prosocial behavior scale. The internal consistency coefficient is 0.82.³²

Family functioning

Family functioning was measured by the Family Adaptability and Cohesion Evaluation Scale (FACES IV),³³ a self-report questionnaire assessing family satisfaction and communication levels. Parents and adolescents who reached the age of 12 completed this questionnaire. Cronbach's alpha-Coefficient for FACES IV lies between 0.77 and 0.89.³³

Use and feedback

Use of the Website was examined by analyzing the time spent on the program. After completion of the program, treatment satisfaction was assessed by an evaluation form with open-ended questions, which was developed for this study. Families were asked about the positive/helpful and negative/difficult aspects of the program and responses were categorized. During the study, parents and adolescents responded to a monthly feedback questionnaire, reporting which aspects of FAMOCA were helpful

with regard to their own coping and the family's and children's adjustment (5-point Likert scale).

Statistical analysis

The statistical evaluation was carried out using IBM SPSS Statistics 22.0.³⁴ The recruitment was concluded after the foreseen period of 16 months, but without having reached the target sample size of 90 parent-child dyads. Means, standard deviations, and frequencies of the dependent variables at baseline were evaluated separately for groups. To verify agreement between the responses of parents and children, the Bland-Altman method was used³⁵ measuring mean differences (bias) between two measures, with 95% limits of agreement (LoA). The bias was assumed to be significant if the line of equality was not within the confidence interval of the mean difference.³⁶

Results

Study sample

A total of 35 direct referrals were made to the study, of which 22 families with a total of 36 children were enrolled. Within these families, four children were not eligible due to their age. Two children and two adolescents declined to participate due to lack of time ($n=1$) or lack of interest in the content of the program ($n=2$). In one case, the parents did not provide a specific reason for the child's nonparticipation ($n=1$). The reasons given by the 13 families who did not participate included: not meeting the inclusion criteria ($n=2$), lack of need and time ($n=4$), progression of disease and need of a different kind of support ($n=2$), and no reason ($n=5$). In total, 63 participants (34 parents and 29 children) completed baseline measures (Table 1). Of the 22 enrolled families, seven were assigned to the control and 15 to the intervention group. Nine families (41%) completed all three measures, three (13%) completed the baseline and the 1-year follow-up measures but left out the post-intervention measures, and 10 families (46%) only filled in the baseline measures. There were no significant differences between the families who dropped out and the retained families with regard to either demographic or medical characteristics (e.g. cancer type). Dropout reasons included a parent's death ($n=2$), feeling overwhelmed ($n=1$), lack of time ($n=2$), unable to reach ($n=2$), and no reason ($n=3$). Of the 15 families in the intervention group, seven families (47%) completed all modules, three (20%) completed modules 1 to 3, and five (33%) completed only module 1. Reasons given for completing only module 1 were lack of time ($n=3$), loss of interest in participation ($n=1$) and death of a parent ($n=1$).

Table 1. Sample characteristics of participating families.

Parents characteristics	<i>n</i>	%
Ill parents	20	
Mothers	19	95
Fathers	1	5
<i>Age in years: Mean = 43.2, range = 32–51</i>		
Spouses	14	
Mothers	2	14.3
Fathers	12	85.7
<i>Age in years: Mean = 43.8, range = 34–55</i>		
Highest level of education completed by ill parents		
Low	0	
Middle	10	50
High	10	50
Highest level of education completed by spouses		
Low	0	0
Middle	4	28.6
High	10	71.4
Children and adolescents characteristics		
Children	20	
Daughters	10	50
Sons	10	50
<i>Age in years: Mean = 8.2, range = 4–11</i>		
Adolescents	8	
Daughters	2	25
Sons	6	75
<i>Age in years: Mean = 13.4, range = 12–17</i>		
Family characteristics		
Single-parent families		
Number of children in a family	5	15.2
1	8	36.4
2	11	50
3	3	13.6
Number of children participating in the study per family		
1	11	57.9
2	7	36.8
3	1	5.3

Children’s QoL

Children 3 to 6 years

Mean values were compared with norm mean scores of a normal population (Table 2).³⁷ Children had a *total score* within the norm whereas their parents reported lower scores than the norm in the *total score*. The line of equality for the total score was within the confidence intervals of the mean difference. Overall agreement was good across the total score with no points lying outside the 95% limits of agreement. Parents additionally filled in the subscales for their children. They reported lower scores in all subscales compared with the norm.

Children 7 to 17 years

Mean values were compared with norm mean scores of a normal population (Table 2).³⁸ Parents reported slightly lower scores for their children compared with norm values in the *total score* and the subscales *physical well-being*, *emotional well-being*, *well-being in the family* and *well-being*



Table 2. Means, standard deviations, and Bland-Altman limits of agreement of children's QoL and behavioral-emotional well-being.

	Baseline									
	Norm-values	Parents M (SD)	Parents ^a M (SD)	Norm-values	Children M (SD)	Bland-Altman LoA	M _{difference}	SD _{difference}	CI of M _{difference}	
KINDL-R (3–6 years)										
Total score	80.0	n = 7 78.00 (7.28)	73.43 (1.90)	73.0	n = 7 73.43 (1.90)	-19.07; 9.93	-4.57	7.44	-11.45; 2.31	
Physical well-being	80.2	n = 14 74.55 (17.24)	-	-	-	-	-	-	-	
Emotional well-being	83.0	79.76 (14.04)	-	-	-	-	-	-	-	
Self-worth	73.6	72.32 (15.25)	-	-	-	-	-	-	-	
Well-being in the family	80.7	75.00 (21.78)	-	-	-	-	-	-	-	
Well-being related to friends	79.7	74.55 (12.85)	-	-	-	-	-	-	-	
School-related well-being	83.8	78.57 (13.59)	-	-	-	-	-	-	-	
KINDL-R (7–17 years)										
Total score	76.9	n = 37 75.87 (11.54)	n = 22 75.83 (10.19)	73.0	n = 22 77.70 (7.33)	-17.95; 14.22	1.87	8.25	-1.79; 5.53	
Physical well-being	77.2	76.01 (20.28)	74.66 (18.89)	70.7	76.99 (14.35)	-39.58; 34.92	2.33	19.10	-6.14; 10.78	
Emotional well-being	80.9	77.03 (14.66)	77.01 (13.54)	81.6	76.42 (11.07)	-25.82; 27.00	-0.59	13.54	-6.59; 5.41	
Self-worth	69.7	74.49 (13.21)	75.22 (11.14)	58.4	72.16 (15.16)	-28.26; 34.38	-3.06	16.06	-10.18; 4.06	
Well-being in the family	78.3	74.83 (15.34)	74.41 (13.06)	82.5	84.09 (10.16)	-38.12; 18.76	9.68	14.58	3.22; 16.15	
Well-being related to friends	78.0	77.70 (13.38)	77.33 (12.50)	77.5	79.83 (8.82)	-25.82; 20.82	2.50	11.96	-2.80; 7.80	
School-related well-being	77.0	75.17 (19.40)	75.86 (17.51)	67.2	76.70 (20.23)	-27.19; 25.51	0.84	13.52	-5.15; 6.83	
SDQ										
Total score	8.4	Parents M (SD) n = 59 9.61 (4.99)	Parents ^b M (SD) n = 8 8.63 (4.10)	Norm-values 10.3	Children between 12 and 18 years M (SD) n = 8 10.63 (3.07)	Bland-Altman LoA -5.66; 9.66	M _{difference} 2.00	SD _{difference} 3.93	CI of M _{difference} -1.29; 5.28	
Emotional symptoms	1.9	2.53 (2.18)	2.38 (1.96)	2.8	2.88 (2.42)	-3.54; 4.54	0.50	2.07	-1.23; 2.23	
Conduct problems	1.6	1.92 (1.52)	1.38 (1.06)	2.2	1.25 (0.89)	-2.32; 2.07	-0.13	1.13	-1.07; 0.82	
Hyperactivity/inattention	3.5	3.56 (2.58)	3.50 (2.62)	3.8	4.00 (1.07)	-3.67; 4.67	0.50	2.14	-1.29; 2.29	
Peer relationship problems	1.5	1.61 (1.59)	1.62 (1.51)	1.5	2.50 (1.51)	-2.49; 4.24	0.88	1.73	-0.57; 2.32	
Prosocial behavior	8.6	9.61 (4.99)	8.25 (1.04)	8.0	8.38 (1.19)	-3.24; 3.49	0.13	1.73	-1.32; 1.57	

Note: ^aParents proxy reports of children who filled out self-reports; ^bParents proxy reports of children between 12 and 18 years; M, Mean; SD, Standard deviation; LoA, 95% limits of agreement; M_{difference}, mean difference; CI, confidence interval; SDQ, Strengths and Difficulties Questionnaire. Higher scores in the KINDL-R reflect better ratings; higher scores in the SDQ reflect greater problems, except for the prosocial behavior subscale.

related to friends, and school-related well-being. Children showed scores within the norm for all scales except for the subscale *emotional well-being*, in which they scored lower. For all scales, the line of equality was within the confidence intervals of the mean difference except for the subscale *well-being in the family*, which may indicate a discrepancy between children’s and parents’ reports (95% CI Mean of difference; 3.22–16.15). Overall agreement was good across all scales with no points lying outside the 95% limits of agreement.

Children’s behavioral–emotional adjustment

Mean values were compared with norm means of a normal population (Table 2).³⁹ Children showed higher means compared with the norm in the subscales *hyperactivity/inattention* and *peer relationship problems*. Parents rated their children between 12 and 18 years higher in the subscale *emotional symptoms*. Parents rated children of all ages higher than the norm in the *total score* and the subscales *emotional symptoms* and *conduct problems*. For all scales, the line of equality was within the confidence intervals of the mean difference. Overall agreement was good across all scales of SDQ ratings with no points lying outside the 95% limits of agreement.

Family functioning

Of all, 82.4% of parents and 87.5% of adolescents rated communication levels between high and very high; 23.6% of parents and 50% of adolescents rated family satisfaction levels between high and very high, while 44.1% of parents and 25% of adolescents rated satisfaction level between low and very low (Table 3).

Table 3. Frequencies, means, and standard deviations of communication and satisfaction levels of parents and adolescents (12–18 years).

		Baseline			
		Parents(n = 34)		Adolescents(n = 8)	
FACES-IV		n (%)	M (SD)	n (%)	M (SD)
Communication level	Very low	1 (2.9)	73.47 (22.27)	0	80.25 (10.34)
	Low	2 (5.9)		0	
	Moderate	3 (8.8)		1 (12.5)	
	High	14 (41.2)		3 (37.5)	
	Very high	14 (41.2)		4 (50.0)	
Satisfaction level	Very low	5 (14.7)	45.18 (24.86)	1 (12.5)	62.25 (27.71)
	Low	10 (29.4)		1 (12.5)	
	Moderate	11 (32.4)		2 (25.0)	
	High	5 (14.7)		2 (25.0)	
	Very high	3 (8.8)		2 (25.0)	

Note: M, mean; SD, standard deviation; FACES-IV, family adaptability and cohesion evaluation scale. FACES-IV levels can vary from “very low” to “very high”.

Time spent on the Website and feedback

On average, participants spent 32 minutes on the Website. Parental feedback was given by phone after completing the program. The content of the Website corresponded to the experiences of parents, reassuring them that their diagnosis-related reactions toward their children were adequate. In general, families appreciated the variety of provided information and the freedom to work independently with the program and the monthly phone contact with the psychologist. Children and adolescents liked the active parts of the program (e.g. storybook). Most families criticized that FAMOCA provided too much text to read; some patients mentioned concentration problems due to cancer treatment and children were challenged with their daily schedule. [Table 4](#) provides the categorized feedbacks.

Parents' monthly feedback about the helpfulness of the FAMOCA program for themselves, for the family and for the children showed average scores between 2.6 and 3.3 ($n = 12$). Adolescents' monthly rating showed average scores between 3 and 3.6 ($n = 3$).

Discussion

A primary aim of this randomized controlled web-based intervention study was to describe children's well-being and QoL as well as family functioning shortly after a parent's cancer diagnosis by comparing the perspective of children and parents, respectively. Additionally, feedback on the benefits and drawbacks of working with the program was evaluated.

Our main results suggest an oligosymptomatic adjustment process to the parental cancer diagnosis with children and adolescents showing no clinically relevant levels of behavioral and emotional problems and normal levels of QoL. This is congruent with former research reporting that approximately 70% of the children with a parent who has cancer do not show increased levels of substantial psychosocial problems, while 30% of them respond more severely to the diagnosis.^{10,14,19} These findings in children are comparable with the number of adults with severe distress symptoms compared with those with transient distress symptoms.^{7,9} Increased levels of distress are mostly associated with adverse family and parenting variables, such as poor family functioning, maternal depression, or low parental QoL.^{13–15,18} In our study, family functioning with regard to family communication was rated as high to very high by the majority of parents and adolescents. On the other hand, the ratings for level of family satisfaction, a measure for the degree of how happy and fulfilled family members feel with each other, were low in both groups. The disclosure of a cancer diagnosis may lead to concerns and destabilization of the family system which can cause lower levels of family satisfaction. However, the premorbid

Table 4. Feedback of families on the FAMOCA program.

Positive Feedback on the FAMOCA program (What did families like the most? What was helpful?)	
Parents	<ul style="list-style-type: none"> Context of the program corresponded to own experiences, which strengthened the belief that their responses and actions were adequate ($n = 11$) <i>"I felt reassured that we informed our children early enough"</i> Variety of provided information ($n = 8$) Working independently with the program ($n = 3$) <i>"We liked that we did not have to find one schedule for all family members together"</i> Recommendations on how to talk with the children and each other ($n = 4$) <i>"Good to receive support talking with the children and knowing how important it is, since they feel the change anyway"</i> Working as a family together on the program ($n = 2$) <i>"It was nice to spend time with my husband working together on FAMOCA"</i> Monthly phone contact with the psychologist ($n = 6$) Specific questions and concerns were addressed during the program ($n = 5$) Children asked more questions ($n = 2$) Relaxation exercises ($n = 9$) Examples of songs ($n = 1$) <i>"Downloading the songs was better than reading"</i>
Adolescents	<ul style="list-style-type: none"> FAMOCA helped finding specific information ($n = 5$)
Children	<ul style="list-style-type: none"> Storybook ($n = 8$) <i>"My children could hardly wait for the children's story book"</i> Handicraft instructions ($n = 7$) <i>"We loved the artwork of the sorrow doll"</i> Downloading songs ($n = 3$) Writing in the diary ($n = 5$)
Negative feedback on the FAMOCA program (What was difficult?)	
Parents	<ul style="list-style-type: none"> Too much text ($n = 8$) <i>"Since my concentration was low, the text was too long for me to read"</i> No new content, only helped shortly after diagnosis ($n = 5$) <i>"Some information came too late because I am already through with the chemo"</i> Too many and difficult questionnaires ($n = 4$) Exhausting to accompany the children through the different modules ($n = 2$) Lack of time ($n = 4$) <i>"Family time is already limited. We did not want to spend it in front of the computer"</i>
Adolescents	<ul style="list-style-type: none"> Too little information for single parents ($n = 1$) Too much text ($n = 2$) No time and no interest in the content of the program ($n = 2$) No need, found information elsewhere ($n = 4$) Too much confrontation with cancer ($n = 4$)
Children	<ul style="list-style-type: none"> Too much to read ($n = 5$) Worksheets remind of school ($n = 1$) Children have enough challenges from school ($n = 2$) Little time or lack of motivation due to a full daily schedule ($n = 5$)

degree of satisfaction and happiness in these families is unknown. Child self-reports on QoL and behavioral-emotional adjustment did only differ in family-related QoL from parent proxy reports, which may imply an underestimation of QoL in this dimension when judged by parents as compared to their children. Parents tended to report lower scores as compared to

their children in overall measurements of QoL and behavioral–emotional adjustment. Previous findings showed that parents reported fewer behavioral and emotional problems and lower QoL scores in their children than the children reported.^{10,14,40}

As this is the first study in Switzerland to evaluate an online tool in a family setting, it was especially important to analyze and understand the benefits as well as the drawbacks of the participants using the program. In general, FAMOCA was appreciated and its influence on the adjustment process was rated as moderate. Families felt taken care of and reported that their specific questions and concerns were addressed. Having support in how to communicate with each other seemed to be an important issue. The interactive parts, with relaxation exercises and handicraft instructions were perceived as useful. The children storybook was generally appreciated. However, the resources of the parents and children to work on the program were limited. Family time was restricted due to cancer treatment and daily tasks and, consequently, activities unrelated to the parent's cancer were often preferred to working on the program. Adolescents preferred other sources of information and for some parents the program did not add to what they knew already. Accordingly, the program was especially helpful for families with a newly diagnosed parent. In these cases what was needed was low-threshold support and specific information on cancer and family rather than intensive psycho-oncological care.

Limitations

This study has some limitations. Generalizability is limited due to a possible selection bias. Our sample mainly consisted of families with no migration background, good general resources and a high income and education level. The response to cancer is influenced by the cultural background of the patient and his or her family. Most of the couples were married and in most cases the mother suffered from breast cancer. Therefore, the informative value is limited to the described study population. Besides, the program was only available in German.

The small sample size was a key limitation and precluded studying intervention effects. Recruitment turned out to be one of the major challenges. Assuming that the population studied was familiar with the Internet, study information was posted on cancer specific Websites focusing on psychosocial issues. We expected that affected parents would contact the study team more often as the FAMOCA Website appeared within the top 5 to 10 positions when searching for family, cancer, and support on German google Websites. In our study, face-to-face recruitment was more

powerful than passive online recruitment. Of the 22 participating families, only three signed in for the study over the Internet, whereas 14 were recruited by their attending physician or psycho-oncologist. However, the number of patients directly referred remained low. Physicians' workload, the predominance of purely medical compared with psychosocial issues may count for the low number of families recruited by oncology staff. Accordingly, a significant personal and financial investment is necessary to create a campaign with a certain impact in which patients are directed to and motivated for an online-study by a trustworthy health care team. Therefore, health care teams need to be trained to identify families at risk.

Attrition from the study was high: 54% of the participants completed post-treatment measures and 41% follow-up measures. One frequently mentioned dropout reason given by children and adolescents was lack of time or loss of interest. Baseline data of children and adolescents were mostly within the normal range, which indicates a good adjustment to the parental cancer diagnosis. After being initially motivated and curious children and adolescent might later have lost momentum due to their daily routines. In line with previous research on what families need, the content of the program was created according to the presumed concerns arising immediately after disclosure of diagnosis, such as how to talk about cancer within the family. However, nearly one third of participating families completed module one only and then dropped out. One reason could be that families thought themselves as being beyond the point where additional information and exercises on family and partnership communication could be beneficial. Not fully met expectations of participants have been suggested to be one reason for low engagement in web-based interventions.⁴¹ Reflecting the demands of a long-term adjustment process after a parental cancer diagnosis, the modules focusing on dealing with emotions and enhancing coping strategies were found to be helpful by the remaining sample. Because FAMOCA contains various components, more research is needed to define in detail which components are more beneficial than others.

The enrollment rate was poor, with 22 participating families compared with the 90 required to achieve an 80% participation rate. One possible reason could be that the burden of affected families to deal with a cancer diagnosis on the one hand and to maintain the daily routines on the other hand is so heavy that participating in a study may at first seem more like an additional strain than a relief. This corresponds to the fact that the majority of the participating families were already in the process of receiving cancer treatment when a first adjustment process had already been made. In addition, interest in participating in support interventions seems to be low in newly diagnosed patients.²¹

Conclusion

To our knowledge, this study is the first in Switzerland evaluating a web-based intervention program for the entire family affected by parental cancer. Due to the small sample size evidence about the feasibility of the FAMOCA program is limited. Baseline data of children and family parameters revealed a good spontaneous adjustment to the cancer diagnosis, which may have influenced attrition rate. Future studies need to investigate how to better address the population in need—families with psychosocial cancer-related difficulties and families with a higher preexisting psychosocial burden and lower income, respectively. As support offers will be more readily accepted when recommended by a health care team, referrals to counseling may be more successful if made by the attending physician. Future studies should invest in the development of appropriate screening instruments and training of medical staff in the detection of distressed families. Additionally, future studies should focus on identifying the subgroups of families in need of psychological support and to implement this knowledge into the recruitment procedure. According to the participants' feedback concerning improvement of the Website, all modules of FAMOCA should be made accessible simultaneously. Families may then decide freely which of the chapters of the different modules (e.g. communicating with adolescents) would apply to them. Furthermore, the text should be shortened, because, participant's motivation to follow short and concise recommendations was higher compared with having to extract the important pieces of information from a written text without these specific instructions. Almost all families appreciated recurrent monthly telephone contact. Therefore, it would be interesting to filter out families likely to benefit rather from a direct therapist contact than from the web-based format. In general, further research is needed to develop made-to-measure cancer-related interventions for the children, the parents, and the whole family.

Implications for psychosocial oncology

- This first web-based program for the entire family including young children affected by parental cancer showed favorable adjustment to the parental cancer diagnosis in the majority of participants. Parental assessment of the children's well-being tended to be lower than children's self-reported assessment.
- Low recruitment rates and high dropout rates may hamper the use of such programs, particularly for children. Therefore, face-to-face counseling and step-up programs may not be fully replaceable by Web-

based programs. However, such programs are feasible and the majority of participants report on substantial support.

- The focus of such programs should be on providing cancer-specific information, on dealing with emotions, and on enhancing coping strategies.

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7.2. Feasibility of minimal contact interventions is limited in couples affected by a new cancer diagnosis

RUNNING TITLE: Feasibility in minimal contact interventions in couples with cancer

Feasibility of minimal contact interventions is limited in couples affected by a new cancer diagnosis

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Abstract

Objective: Patients with recently diagnosed cancer show high rates of distress and may develop depression and anxiety. Their partners are also affected by psychosocial stress, but interventions aiming at couples remain to be a challenge. Therefore, this study examined the feasibility of minimal contact interventions and psychological adjustments in couples immediately after a cancer diagnosis.

Methods: Observational study on minimal contact interventions using psychometric testing in patients and their partners before and 16 weeks after initial therapy, typically surgery, followed by chemotherapy. Depression, anxiety, optimism, pessimism, and quality of relationship were assessed. Written information conveyed to all eligible patients, a specifically designed homepage, and active personal information of all oncologists in the University Hospital Basel were used for recruitment. Feasibility was defined as an inclusion rate over 50% in eligible couples and a dropout rate under 50% in couples included.

Results: 292 couples were eligible, 33 couples showed interest and were screened, and 20 patients and 14 partners could be included. 17 patients underwent surgery and chemotherapy. Inclusion rate was 61% in patients screened and 7% in patients eligible. Dropout in patients at 16 weeks was 50%. Anxiety was pronounced at diagnosis in patients and partners, but decreased during follow-up. Optimism was subdued at diagnosis, but increased during follow-up.

Conclusion: Feasibility of minimal contact interventions was limited in our sample, if eligible patients were to be considered. However, the majority of effectively screened patients could be included, half of them showing high adherence. It remains unclear, if improvements in optimism and anxiety can be attributed to the minimal contact interventions. We conclude that minimal contact interventions may be used for the support of couples affected by parental cancer, but the majority of patients and partners do not actively reach out to use such programs.

Objectives/Introduction

Cancer not only affects patients, but also nearest relatives and particularly partners (2004; Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008). A new cancer diagnosis confronts patients and those close to them with an enormous amount of psychosocial stress (McClure, Nezu, Nezu, O'Hea, & McMahon, 2012), challenging psychosocial adjustment, communication, coping, and social support of those directly and indirectly affected (Brandao et al.). Rates of depression and anxiety are significantly higher in cancer patients than in the general population with point prevalence estimates of about 20% (Linden, Vodermaier, Mackenzie, & Greig, 2012; Mitchell et al., 2011). Similar findings were found in partners of patients with cancer (Mitchell et al., 2011). While overt depression and anxiety was described in 10% of partners, subclinical signs were found in up to 30%. Considering this, several couple-based face-to-face interventions to improve the patients' and partners' quality of life have recently been published (Li & Loke, 2014). However, due to a certain lack of knowledge on spousal communication (Badr, 2017) and limited resources, effective psychosocial interventions are not conveyed to all families in need – even in high-income countries, such as Switzerland, where over 40% of patients undergo in-hospital rehabilitation (Ture et al., 2015).

Here, minimal contact interventions, such as programs based on written information or information provided by the Internet, could possibly serve as tools to support patients and partners with newly diagnosed cancer. The strengths of these interventions are the low cost, the high standardization, and particularly the independence of time and place. This may be specifically important to partners who mostly remain in their social and work-related routine. However, disadvantages of minimal contact interventions are missing personal contact to psycho-oncologists, as well as a pronounced dependency on information technology, health literacy, and motivation to use the provided information independently. Minimal contact interventions have proven effects in many different fields, such as anxiety (Axelsson, Andersson, Ljotsson, & Hedman-Lagerlof, 2018), irritable bowel syndrome (Pajak, Lackner, & Kamboj, 2013), and depression (Newman, Szkodny, Llera, & Przeworski, 2011). Unfortunately, there are only limited results regarding feasibility and efficacy in such interventions focusing on patients (Urech et al., 2018) or families (Bingisser et al., 2018) in newly diagnosed cancer. One

of the problems reported with minimal contact interventions was the low inclusion and the high dropout rate (Badr & Krebs, 2013; Zimmermann, 2015) or generally speaking the feasibility of such programs. We therefore report on the feasibility, as defined by inclusion rate and adherence, of minimal contact interventions in patients and their partners with underage children during the first 16 weeks of cancer therapy in a Swiss University hospital. Specific aims were to study use and adherence to the programs and report on psychological adjustment in patients and partners at inclusion and after 16 weeks on the minimal contact intervention.

Methods

We collected data as a part of the randomized controlled web-based intervention study “FAMOCA – family online counselling for families with parental cancer” aiming to improve psychological adjustment in families of newly diagnosed cancer patients. This program was developed based on cognitive-behavioural therapy interventions by focusing on psycho-educative elements, enhancing open communication, affective involvement, family and relationship cohesion, problem-solving skills, and adaptive coping at the level of the individual, the couple, and the family. The detailed description of the program can be found in a recent publication (Bingisser et al., 2018). Informed consent was obtained from all individual participants (patients and partners). Ethic approval was obtained from the responsible local ethics board (EKNZ 38/13).

Participants and inclusion criteria

Eligible patients had to present with a newly diagnosed cancer (within last month), an expected progression free survival of 12 month, at least one child between 3 and 18 years, and with sufficient German speaking and reading skills.

Procedures

Patients were recruited by provision of leaflets in their information folder at hospitalization, in waiting rooms, and online forums between March 1st 2013 and June 30th 2015. Families were motivated to contact the research team by oncologists, through the website, by email or by telephone. Participants were provided with detailed information and terms of participation. A written informed consent form was individually obtained from all participants. After screening of all patients showing active signs of

interest through an email contact or a phone call, participants were assigned either to an internet-based intervention or a comprehensive self-administered written information, based on contents provided by the Swiss and German Cancer Leagues. Patients and their partners had regular email contact with the study team in both groups, and monthly assessments on the use of support, treatment satisfaction, coping, and individual wellbeing.

T1 was defined as the start of the program, and T2 was defined as the completion of the intervention, 16 weeks after T1. Participants filled in identical questionnaires (see below) at T1 and T2. The number of eligible patients with newly diagnosed cancer and underage children were retrieved from the hospital's electronic health records (EHR). Reasons for non-enrolment of screened patients were recorded; they were categorized into failure to meet inclusion criteria, (e.g. inadequate computer skills, palliative treatment, lack of family member availability), lack of time (e.g. due to family schedules), and unwillingness to participate.

Measures

Demographic and cancer specific data were gathered from self-reports and medical reports using the EHR. Demographic data included age, gender, marital status, number of children, educational level, monthly income, cancer diagnosis, and type of treatment (see table 1). In both groups, questionnaires were to be completed online at T1 and T2, and included the following tools:

Depression and Anxiety: To assess the patients' and partners' anxiety and depression, the German version of the Hospital Anxiety and Depression scale HADS was utilized (Herrmann-Lingen, Buss, & Snaith, 2011). The HADS is a self-report questionnaire, which has been specifically developed for physically ill patients. It consists of 14 items and is divided into an *Anxiety* subscale (*HADS-A*) and a *Depression* subscale (*HADS-D*), both containing 7 items. The items are scored on a 4-point Likert-scale ranging from 0 to 3. Cronbach's alpha across different studies varies between $\alpha = .68$ and $\alpha = .93$ (mean $\alpha = 0.83$) for *HADS-A* - and between $\alpha = .67$ and $\alpha = .90$ (mean $\alpha = .82$) for *HADS-D*. Cut-offs were defined as ≥ 9 (9/21) for *HADS-A*, and ≥ 8 (8/21) for *HADS-D*, because of the equilibrium of sensitivity (.80) and specificity (.80).

Optimism and pessimism: The German Version (Herzberg, Glaesmer, & Hoyer, 2006) of the Life Orientation Test (LOT-R) is a revised version of the original LOT (Scheier, Carver, & Bridges, 1994) a 10-item measure of optimism versus pessimism. Of the 10 items, 3 items measure optimism (LOT-O), 3 items measure pessimism (LOT-P), and 4 items serve as controls. Respondents rate each item on a 4-point scale: 0 = *strongly disagree*, 1 = *disagree*, 2 = *neutral*, 3 = *agree*, and 4 = *strongly agree*.

Quality of marital relationship: The self-reports of quality of marital relationship were evaluated with a marital relationship questionnaire *Partnerschaftsfragebogen* PFB (Hahlweg, 1996). The questionnaire contains three subscales, *conflict behaviour*, *tenderness*, and *communication*. Each subscale consists of 10 items, which is scored on a 4-point Likert scale ranging from 0-3. Sum scores range from 0-90 and high sum scores indicate a high quality of marital relationship. Cronbach's alpha for the three subscales are $\alpha = .88$ for *conflict behaviour*, $\alpha = .91$ for *tenderness*, and $\alpha = .85$ for *communication*. The following cut-offs were used: *conflict behaviour* 5.4; *tenderness*: 20.1; *communication*: 20.1; *total sum score*: 64.9 (16).

Coping styles: The German Version of the Brief COPE (Carver, 1997) consists of 28 Likert-scaled items and assesses 14 coping styles: self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioural disengagement, venting, positive reframing, planning, humour, acceptance, religion, and self-blame. Each item was scored on a 4-point scale; each category contained two questions of maximum 4 points each. The number of points are an indication for the style of coping, the maximum per category being 8 points.

Statistical analyses

The statistical evaluation was carried out using IBM SPSS Statistics 22.0 (IBM Corp.). Means, medians, and distributions were calculated separately for all groups and time points. For comparisons, two-tailed Wilcoxon signed-rank or T-tests were used for dependent samples, and Levene tests for independent samples, where appropriate.

Results

292 patients were theoretically eligible between December 1st 2013 and June 30th 2015 according to the hospital's database. 33 patients actively contacted the study team, and 13 patients could not be included due to palliative treatment in two patients, lack of family member availability in two patients (either partner or children unwilling or unable to participate), restricted family schedule (school, sports) in four patients, and unwillingness to sign informed consent for no specific reason (see figure 1). Also, one couple was formally included, but had to be excluded due to unexpected early death. In sum, 20 patients consented to the study resulting in an enrolment rate of 61% in screened patients and 7% in eligible patients, respectively.

Seven couples (13 patients, 9 partners) were assigned to the internet-based intervention and five couples (7 patients, 5 partners) were assigned to the self-administered information intervention. In order to assess the feasibility and effects of minimal contact interventions, patients and partners were pooled, respectively. There were no significant differences in demographic or outcome variables between the groups, as well as between participants completing the program and dropouts at T2. Demographics are shown in table 1. For comparisons between T1 and T2, dropouts were excluded. Patients included suffered from the following cancers: 13 had breast cancer, 2 had lung cancer, and 5 had gallbladder, cervix, appendix, pancreatic, and skin cancer, which were treated with 17 chemotherapies, 17 surgeries, 12 radiotherapies, and 12 other therapies.

Depression and Anxiety: HADS-D for depression showed sub-threshold (<8) scores in the majority of patients (median 6) and partners (median 6.5) at T1, without significant change at T2 ($t=1.38$, $p=0.20$). HADS-A for anxiety levels were above the cut-off (≥ 9) scores in the majority of patients (median 11) and partners (median 10), with significant decrease in patients at T2 ($t=3.23$, $p=0.01$) (see table 2).

Optimism and pessimism: LOT-P showed mildly elevated pessimism scores for the majority of patients (median 4.5 of 12) and partners (median 3 of 12) at T1, without significant change at T2 ($t=-0.12$, $p=0.91$). LOT-O showed subdued optimism scores for the majority of patients (median 5 of 12) and partners (median 6 of 12), without significant increase in patients at T2 (see table 2).

Quality of marital relationship: PFB showed intermediate scores for the majority of patients (median 69.5 of 90) and partners (median 52.5 of 90) at T1, without significant change at T2 ($t=1.27$, $p=0.22$). Sub-scores were comparable between patients and partners; the only exception being a significant difference in the rating of conflict behaviour between patients (median 5) and partners (median 9) at T1 ($t=-2.17$, $p=0.04$). This difference was consistent at T2 (see table 2).

Coping styles: The BCOPE at T1 and T2 showed high scores (6 to 8 points) for the following coping styles in patients: active coping, use of emotional support, instrumental support, positive reframing, planning, and acceptance. Ratings of partner and patient's BCOPE measures at T1 and T2 showed low scores (2 to 4 points) for the following coping styles: denial, substance use, behavioural disengagement, humour, religion, and self-blame (see table 3).

Discussion

The main finding of our study was the limited feasibility of minimal contact interventions in newly diagnosed cancer, if the inclusion rate of theoretically eligible patients was taken as the definition. However, the majority of effectively screened patients were willing to participate, and full adherence to the interventions was shown in 50% of all patients. Possible reasons for the low participation of eligible patients were the form of recruitment via oncologists and written information at hospitalisation, the timing around the start of cancer therapy, and the competition with face-to-face counselling. The majority of withdrawals at screening were due to time issues and lack of interest. This finding supports the experience of many caregivers at the start of cancer therapy, particularly in patients with underage children: The most often female patients are overwhelmed by the dramatically new situation, dominated by healthcare appointments and simultaneous organisation of occupation, family and other social chores. It must be pointed out that patients with children are in an age group demanding to the entire family regarding career, child raising, finances, and social integration. Particularly women tend to take over many different roles, and the raising of the children is in their utmost interest – a steady state has often not been reached.

Therefore, newly diagnosed cancer may severely hit an entire family; an already complex schedule is completely thrown over. All these problems may explain difficulties in inclusion and adherence in families affected by parental cancer.

Patients with cancer generally have a low rate of psychosocial conditions at diagnosis, in spite of a high distress, but may develop depression and anxiety disorder in the course of disease (Henselmans et al., 2010). In our patients, there was a high level of anxiety at inclusion, with a decrease during the first 16 weeks of therapy. Optimism was restrained at the start of therapy, but increased at follow-up. Interestingly, our patients reported several positive coping styles - with markedly high scores – such as active coping, the use of emotional support, the use of instrumental support, positive reframing, planning, and acceptance. These strategies have been shown to be associated with quality of life in cancer patients (Shapiro, McCue, Heyman, Dey, & Haller, 2010). Similarly, the BCOPE showed low scores for negative coping styles such as denial, substance use, behavioural disengagement, and self-blame. Taken together, the participating patients and partners seemed highly selected for positive behavioural traits. Furthermore, monthly feedbacks with psycho-oncologists showed high emotional and communicative skills in almost all patients included.

How do these results compare to the literature? First, there is very little evidence for minimal contact interventions, and almost none in families with newly diagnosed cancer. A recent study (Urech et al., 2018) showed that quality of life was significantly higher and distress significantly lower in an intervention group using a web-based minimal contact program, as compared to a group waiting for intervention. However, changes in anxiety or depression were not significant in the intention-to-treat population. Further, recruitment was more actively carried out, and an inclusion rate of over 50% was reported. However, this study was performed in patients only, irrespective of family participation, and the inclusion period was extended to three months after the start of first-line therapy as compared to one month after diagnosis in the present study. One might conclude that three months are more suitable in such interventions, as the first month is a specifically vulnerable period. However, effects of an intervention may be different and even less needed three months after the start of therapy. Comparable minimal contact interventions have so far only shown general

acceptability (Karageorge et al., 2017), they have been restricted to physical activity behaviour change (Forbes, Blanchard, Mummery, & Courneya, 2017), or they have focused on the role of the therapeutic facilitator (Carter, Fergus, Ahmad, McLeod, & Stephen, 2015). In our opinion, minimal contact interventions may have a place in the future, particularly in the early phase of cancer treatment in individual patients, but possibly also in their partners. Unfortunately, the benefit of psychosocial interventions for couples coping remains unclear (Zimmermann, 2015), partly due to recruitment problems. A recent meta-analysis showed that almost half of all interventions recruited less than 35 couples per group, refusal rates reaching 82% (Badr & Krebs, 2013). To be prudent, one might conclude that the novel tool of minimal contact intervention is yet another possibility to support families affected by parental cancer. Reasons for low recruitment and considerable dropout cannot be finally judged, the necessity to use computer and Internet being one of the possible reasons. On the other hand, the present results show similar dropout rates in patients and partners provided with written information, which puts the Internet as a deterring mechanism into perspective. Certainly, increasing habituation to Internet technology will support the use of minimal contact interventions in the future. Nevertheless, more studies are needed in search of the reasons of low inclusion and high dropout in minimal contact interventions in order to facilitate the use of such cost-effective and highly standardised tools.

Limitations

This study has multiple limitations. First, the number of participants was low. Therefore, a differential assessment of outcomes regarding the two different minimal contact interventions was not possible. Second, most patients included were women with breast cancer. They tend to undergo most of their therapy in an ambulatory setting. According to a recent publication in Switzerland (Ture et al., 2015) they do not use in-patient rehabilitation facilities very often, which is clearly different in other types of cancer. Therefore, the results should not be generalized. Third, participants were patients in 60% and affected partners in 40%. Individually differing reactions to interventions are well known – therefore, the spread of clinical effects may be even wider in a mixed group of patients and partners. Interestingly, most psychometric assessments were comparable between patients and partners, except for conflict

behaviour, where partners seem more sensitive, while patients might be preoccupied with disease and treatment. Fourth, in spite of one of the big advantages, namely the standardisation of information given using such minimal contact interventions, there is no good evidence on the content of such information (Badr, 2017). Therefore, direct comparison to face-to-face counselling should be attempted, where the individualised contact focusing on the therapeutic relationship could turn out to be an advantage of direct counselling.

Conclusion

Minimal contact interventions, such as an online-program or a comprehensive written information program – in spite of good evidence in other fields – are yet at an early stage in newly diagnosed cancer, particularly if focusing on patients and their partners together. Feasibility may be hampered by the higher effort patients and partners need to take, by the use of information technology, and by the lack of face-to-face counselling, which remains to be the golden standard in patients, partners and children affected by newly diagnosed parental cancer.

Conflict of interest

The authors declare no conflict of interest.

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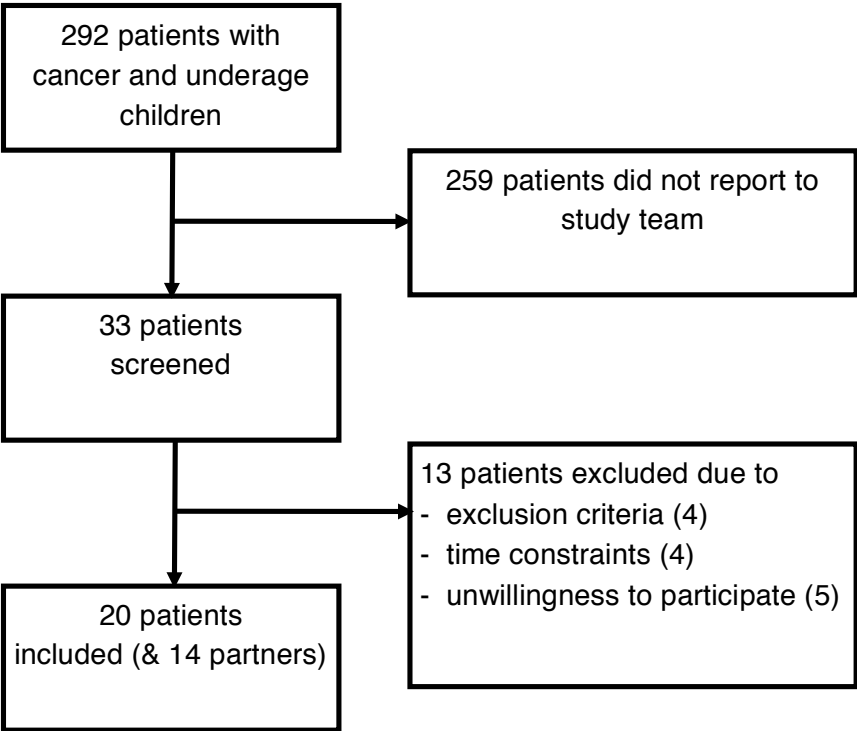


Figure 1: Inclusion

Table 1. Baseline characteristics

	<i>Patients (n = 20)</i>	<i>Partners (n = 14)</i>
Gender		
Male	1	12
Female	19	2
Mean age (years) <i>(SD/range)</i>	43.2 (5.6; 32 – 51)	43.8 (5.7; 34 – 55)
Marital status		
Married	16	13
Unmarried	3	0
Divorced	1	1
Children (n)		
1	7	7
2	10	5
3	3	2
Educational Level		
Low	0	0
Middle	10	4
High	10	10

Table 2. Psychometric testing

	T1 Patients M (range)	T2 Patients M (range)	T1 Partner M (range)	T2 Partner M (range)
HADS	n = 20	n = 10	n = 14	n = 6
Depression	6.00 (13)	5.50 (10)	6.50 (14)	7.50 (16)
Anxiety	11.00 (10)	8.00 (13)	10.00 (10)	6.50 (11)
LOT-R	n = 20	n = 10	n = 14	n = 6
Pessimism	4.50 (15)	3.00 (6)	3.00 (15)	9.50 (11)
Optimism	5.00 (6)	6.00 (8)	6.00 (4)	5.50 (5)
PFB	n = 16	n = 9	n = 12	n = 5
Conflict behaviour	5.00 (11)	5.00 (10)	9.00 (22)	12.00 (17)
Tenderness	20.00 (25)	19.00 (26)	17.00 (26)	13.00 (14)
Communication	22.50 (20)	20.00 (14)	19.50 (22)	19.00 (13)
Total score	69.50 (46)	64.00 (45)	52.50 (55)	45.00 (39)

Note: M: median; n: number of participants; HADS: Hospital Anxiety and Depression Scale; LOT-R: Life Orientation Test; PFB: Partnerschaftsfragebogen (quality of marital relationship)

Table 3. Coping styles

	T1 Patients M (range)	T2 Patients M (range)	T1 Partner M (range)	T2 Partner M (range)
BCOPE	n = 20	n = 10	n = 14	n = 6
Self-distraction	5.50 (4)	4.50 (4)	5.00 (4)	4.50 (4)
Active coping	8.00 (4)	6.00 (6)	5.00 (5)	5.00 (4)
Denial	3.50 (5)	3.00 (3)	3.00 (5)	2.00 (3)
Substance use	2.00 (3)	2.00 (0)	2.00 (5)	2.00 (4)
Use of emotional support	8.00 (5)	7.50 (4)	6.50 (4)	6.00 (3)
Instrumental support	6.00 (5)	6.50 (6)	5.50 (6)	4.50 (6)
Behavioural disengagement	2.00 (1)	2.00 (1)	2.00 (3)	2.50 (4)
Venting	5.00 (6)	6.00 (5)	4.00 (4)	2.00 (4)
Positive reframing	6.00 (6)	5.50 (4)	5.00 (5)	5.50 (3)
Planning	7.00 (5)	6.00 (5)	7.00 (4)	4.50 (5)
Humour	4.00 (6)	4.00 (6)	2.50 (3)	3.00 (2)
Acceptance	6.00 (5)	6.00 (4)	6.00 (6)	6.00 (6)
Religion	4.00 (6)	4.00 (3)	4.00 (5)	4.00 (3)
Self-blame	4.00 (4)	3.00 (2)	2.50 (4)	2.50 (2)

Note: M: median; n: number of participants; BCOPE: German version of the brief COPE tool for coping styles

7.3. Feasibility and acceptability of a short-term counselling intervention for families with parental cancer

Feasibility and acceptability of a short-term counselling intervention for families with parental cancer

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Keywords

Cancer, family functioning, family intervention, gynaecologic oncology, parental cancer, short-term counselling

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Key points:

- Currently, only few counselling programs focusing on psychological support for families of cancer patients exist.
- The present study examined the feasibility and acceptability of a newly developed short-term counselling intervention for families with parental cancer.
- So far, eleven families decided to participate and rated the satisfaction with the content of the counselling.
- First results of this on-going study showed high acceptability and satisfaction of the counselling. Families affected by parental cancer appreciated the possibility of family counselling at the time needed.
- These findings highlight the potential of low-threshold counselling for families affected by parental cancer and approve further research in this area.

Background

A parental cancer diagnosis in families with minor children may have substantial impact on family functioning and well-being of all family members [1]. Parents may be unsettled in their parenting role and children are confronted with difficulties in changes within the family [2]. As a consequence of the diagnosis around one third of patients and 10-30% of their partners develop significant mental health conditions with high prevalence of depression, anxiety and adjustment disorders [3, 4]. About 25-30% of children with a parental cancer are identified with increased levels of emotional and behavioural symptoms, including higher levels of anxiety, depression, aggressive behaviour and reduced self-esteem [5].

As a consequence of the burden on family life due to the disclosure of a parental cancer diagnosis, several counselling concepts for families with parental cancer have been developed. Family-centred interventions seem to have a positive impact on children's and parents' psychosocial well-being, as well as a good acceptance toward the respective interventions [6]. Nonetheless, there is still an overall lack of data on feasibility and effectiveness of these specific interventions [6].

The objectives of the present study was to assess the feasibility and acceptability of a short-term counselling intervention for families affected by parental cancer.

Methods

Design, recruitment and participants

We conducted a randomized wait-list-control intervention study with repeated measures at baseline (T1), post-intervention (T2) and six weeks follow-up (T3).

Families were recruited via information flyer distributed in the cancer care centre of the University Hospital Basel, provider referrals or self-referrals. We included German-speaking families with any kind of parental cancer (diagnosis or relapse within the last 12 months, cancer stages I to III) and with at least one child between 2 and 18 years, who is living with the affected parent. The local ethics committee approved the study (No 2016-01201) and the trial is registered on clinicaltrials.gov (NCT03097458).

Intervention and procedure

The intervention is a six week short-term counselling based on existing and evaluated concepts [7] as well as on our own experiences from a previous study [8]. The intervention aimed to enhance the adjustment in children and parents affected by parental cancer. The content and structure of the counselling is described in Table 1 (see supporting information).

Measures

Feasibility. Feasibility was assessed with number of participants screened for eligibility and enrolled into the study, dropout and retention rates. To measure the enrolment rate, the number of participants screened, the number of eligible families, the number of contacted families and the number of families who consented was tracked. The number of patients with newly diagnosed cancer was retrieved from the hospital's electronic health records (EHR). All cancer patients who were treated at the cancer center of the University Hospital Basel aged from 60 years and younger were screened for eligibility. Demographic and medical information were retrieved from the EHR. Reasons for declining were assessed with a short evaluation form. Furthermore, dropout reasons were assessed.

Acceptability. The German version of the Client Satisfaction Questionnaire-8 (CSQ-8) [9] was given to those families who completed the intervention in order to assess level of satisfaction with the program.

Data analysis

Descriptive statistics were used to characterise the study sample. Quantitative satisfaction measures were reported as means, standard deviations and percentages. To measure differences between families who were enrolled and families who declined, two-tailed t-tests of significance were used. P-values less than 0.05 were considered statistically significant.

Results

Feasibility

During 14 months, 753 cancer patients were screened for eligibility. Of these, 142 (18.9%) were potentially eligible, 611 (81.1%) did not fulfill inclusion criteria. Of the 142 eligible patients, 71 (50%) are within the decision or eligibility process, 60 (42.3%) patients declined to participate and 11 families (7.7%) consented to the study (see supporting information figure 1). Reasons for non-participation were 1) not needing counselling (n=26; 43.3%), 2) children were doing fine (n=12, 46.2%), 3) too busy with current treatment (n=5, 19.2%), 4) other topics were more important (n=5, 19.2%), 5) not wanting to upset their children (n=4, 15.4%). Overall response rate was 18.3% (11/60). Of patients who did not consent to the study, 36 (60%) had already psychological or psycho-oncological support.

Currently, 11 families are enrolled in the study. Age of the parents ranged from 36-49 years (mean=42.3, SD=4.7), children were between 2-18 years (mean=7.9, SD=5.1). The majority of patients had breast cancer (n=8, 80%) and were on average 2.5 months (SD=2.51) after initial diagnosis. Almost all participants were married (n=17, 81.8%) and of higher education (n=18, 90%).

Retention and attrition rate. The intervention was completed by nine families (81.8%) and six of those families (54.5%) completed all follow-up assessments (T1-T3). Dropout reasons were progression of disease with rapid aggravation of the patient (n=1) and not being able to be reached anymore (n=1).

Differences in enrolment concerning demographic variables. Families who declined to participate did not significantly differ from participating families. However, age of children was significantly lower in participating families (M=6.65) compared to children of declining families (M=11.71; $t=-2.82$; $p<.007$).

Acceptability of the counselling

Participating parents and teens were generally satisfied with the counselling (n=16, M=26.56, SD=6.09) with nine parents (56.25%) reporting overall satisfaction level of care with 29 of possible 32 points. All parents indicated that the counselling met most or almost all of their needs. Two parents (12.5%) would not really recommend the counselling to others, twelve (75%) would recommend it to others. Ten parents (62.5%) indicated that they would definitely participate in the counselling again, whereas two parents (12.5%) would probably not.

Discussion

The goal of the present study was to assess the feasibility and acceptability of a short-term counselling intervention for families affected by parental cancer. Our findings suggest that the short-term counselling was appealing and acceptable. Parents rated the counselling as helpful and were satisfied with the format and content of the different sessions. The majority would recommend it to others and participate again. Furthermore, few families withdrew from the study. Retention was high; 81.8% completed post-intervention measures.

Although, acceptability of the counselling was high, the enrolment rate was lower than in other studies [10], indicating a limited feasibility. Comparable to other research, over one third of patients who declined were in no need of additional professional support [1]. About a quarter of them stated that they already have professional support and 59.3% had at least one meeting with a psycho-oncologist. In general, 73% of cancer patients wish to receive information about services to support their children or parenting [1]. Patients who declined to participate in our study may already been satisfied with the received information.

Despite the general demand for more family support, only about 9% receive family-focused support [1]. Families often search for psychosocial support during medical treatment, when their child seems distressed, if they have more than one child or when children are younger [1]. This is in line with our results: participating families had significantly younger children, were under medical treatment and shortly after initial cancer diagnosis. Additionally, users of family-centered counselling report more child-related concerns [10]. Most of our participating parents used the

counselling due to an uncertainty regarding communication with the children or when children showed behavioral changes.

In our sample, the number of patient's children and their age was not systematically assessed in the EHR and is therefore often unknown. Asking patients with newly diagnosed cancer whether they have minor children might ease the recruitment process. Additionally, an appropriate screening tool for physicians to detect those families who are distressed might help to support families at risk. A low-threshold counselling such as our counselling could operate as a door opener for adequate service outside the hospital.

Study limitations

This study has some limitations. The sample size is low with eleven participating families. Further studies with a larger sample size are needed to evaluate the efficacy of the counselling. A sampling bias might have occurred due to the fact that our sample included well-educated, Caucasian, mostly married couples and mainly breast cancer patients.

Clinical implications

A cancer diagnosis affects not only the patient but the whole family. Therefore, it is important to focus on the entire family system and, if necessary, support them individually. Appropriate screening tools for distressed families or even a family session implemented in the usual cancer treatment may facilitate the early detection of families at risk. Furthermore, a low-threshold counselling could help to overcome fear of stigmatization and provide additional psychological services if needed. Every family adjusts individually and in their own time to a parental cancer diagnosis. It is therefore of utmost importance to identify families with need of psychological care

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during the whole cancer treatment and provide them with evaluated and implemented support.

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Conflict of interest

The authors declare no conflict of interest.

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Table 1. Overview of the short-term counselling for families with parental cancer

Session	Content
<p>1 Evaluation of the family situation</p>	<ul style="list-style-type: none"> • Assessment of parent’s experiences with the cancer diagnosis and its impact on the individual, couple, parent and family level. • Questions up to six topics (coping behaviour, changes in daily functioning and partnership, family communication and information transfer from parents to children, concerns about the children and family resources). • Assessment of individual and family’s wishes for the intervention.
<p>2 Diagnostic feedback</p>	<ul style="list-style-type: none"> • Providing of oral feedback on the analysed baseline questionnaires, integrated into the reported problems and wishes of the evaluation phase. • Children have the possibility to report about their understanding of the parental cancer diagnosis and treatment, their coping behaviour and their needs. On this diagnostic basis, the therapist makes support recommendations. • At the end of the session, the family decides if they want to continue with the intervention sessions. • Family chooses if they want to attend all intervention sessions or only specific ones.
<p>3 Intervention dealing with everyday life</p>	<ul style="list-style-type: none"> • Report on changes in daily routines, chores and family functioning. • Interactive part: creation of a family calendar to maintain the overview of the daily chores, appointments and the planning of pleasant and distracting family activities.
<p>4 Intervention dealing with emotions</p>	<ul style="list-style-type: none"> • Psychoeducational overview on the functioning and mechanics of emotions. • Report on their own experiences and how they communicate their feelings to each other. • Interactive part: mindfulness exercise “raisin meditation” (adapted with gummy bears for children).

5	Intervention detecting family resources	<ul style="list-style-type: none">• Exchange within the family about their own strengths and resources.• Interactive part: each family member tells the therapist two skills, which are written on separate cards. One person may draw a card and explain what the skill might imply. In a second step, the family guesses who might have written down the chosen skill. In the end, resources of the whole family are collected and written on cards. The family is invited to take the cards at home as a reminder of their strengths.
6	Final meeting	<ul style="list-style-type: none">• Reflecting the personal changes and progress of each family member.• Helpful strategies that were detected during the intervention are highlighted and consolidated.• Assessment of intervention satisfaction and proposal for amendments for the counselling are inquired.• If indicated, contact addresses to further therapeutic/counselling services are provided.

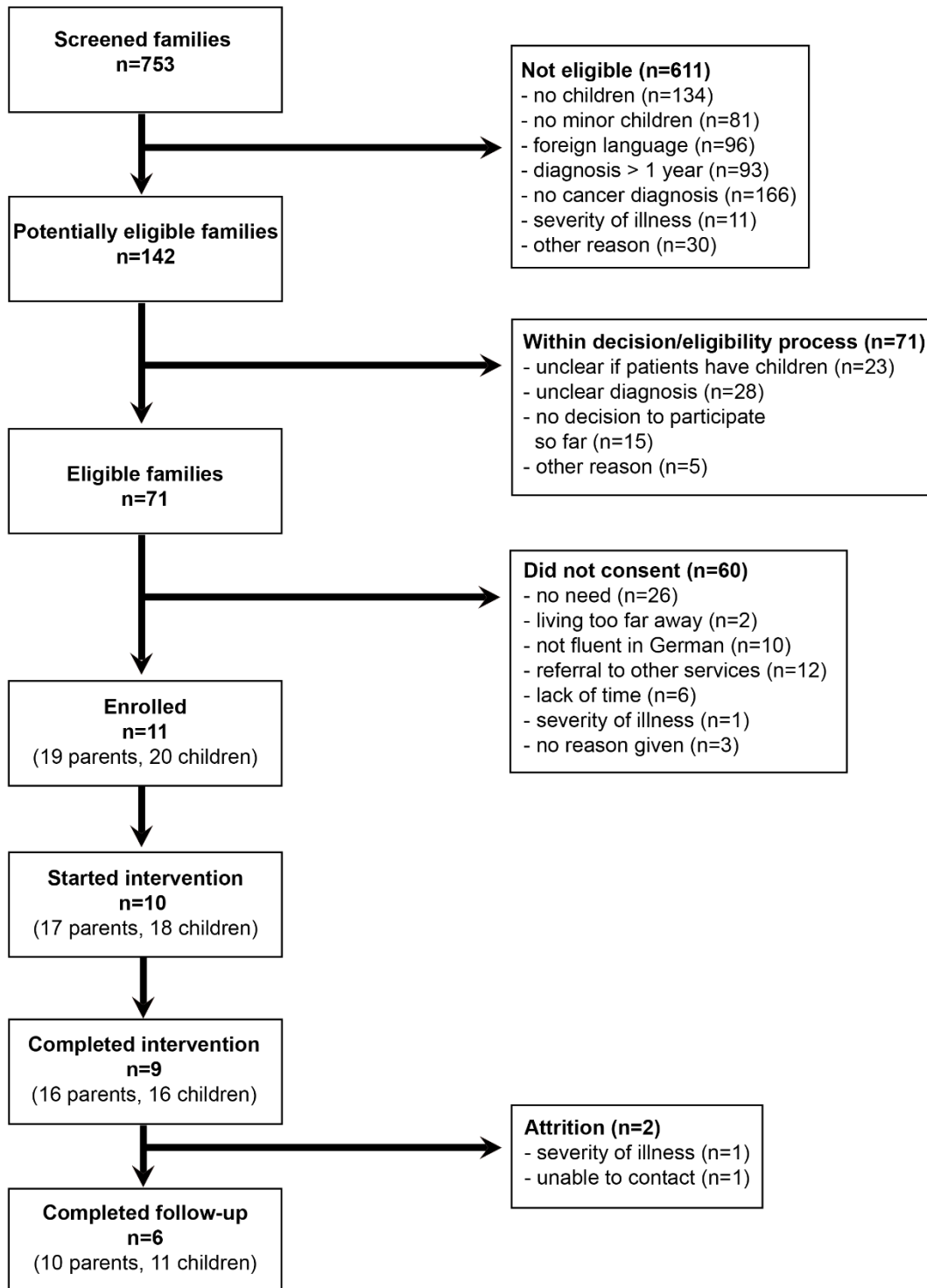


Figure 2. Short-term counselling study eligibility, recruitment, enrolment, and retention flow diagram

8. APPENDIX

8.1. Acknowledgments

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