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Effects of Social Counseling on Parents of a Child With Cancer

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Abstract

When a child is diagnosed with cancer, there can be serious consequences for the entire family. The purpose of this study was to explore the relationship between social counseling based on different social diagnostic methods and parent's quality of life, psychosocial burden, and sense of coherence. Seventy-one parents of children with cancer were randomly assigned to the intervention and control group and were interviewed at three measurement times.

ANCOVA was used for the data analysis. With respect to the effects of social counseling based on different social diagnostic methods, the results are somewhat mixed. We found only few significant effects between the intervention and control groups, but a significant influence of moderating variables, like the child's health status. There were significant changes in parent's quality of life and psychosocial burden but the findings provided no evidence that one social diagnostic method works better than the other one. Methodological reasons concerning sample size and program integrity are discussed.

Keywords: social counseling, social diagnostic, quasi-experimental study, children suffering from cancer, quality of life

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Introduction

On average, approximately 200 children are diagnosed with cancer each year in Switzerland (Bundesamt für Statistik [BFS], 2017). Evidence shows that the psychosocial burden of family members can be just as serious as that of children with cancer. Such effects of cancer and its therapies on the social dimension or the associated social problems are important because in the patient's disease processing, apart from individual characteristics, the psychosocial environment (e.g., family) plays a major role (Muthny & Bengel, 2009, p. 358).

Particularly in the first phase of cancer diagnosis, it is extremely important for parents to be offered professional help as soon as possible. This is where professional social work comes in; social counseling is active support and affects, in a planned manner, the subjective life conduct of individuals in cases where life conduct can potentially become socially problematic. Social counseling aims to reduce strain and burden, to make it possible for people to actively conduct their lives and cope with everyday life, to strengthen their sense of coherence and thus, to improve or at least stabilize the quality of life of families of a child with cancer. Little is known, however, about the effect of social counseling with family members of people with cancer. This project was carried out in cooperation with the social services team at a children's hospital in Switzerland. This study was financially supported by the Swiss Cancer Research foundation.

Situation of Families of Children with Cancer

Childhood cancer is an event that can trigger acute psychosocial burden and have long-term consequences for the child (Darcy, Enskär, & Björk, 2019; Mader et al., 2017a, Kohlsdorf & Costa Junior, 2012; Ravens-Sieberer, Bettge, & Erhart, 2003; Waters, Wake, Hesketh, Ashley, & Smibert, 2003) and for the whole family, especially the parents (Apter, Farbstein,

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& Yaniv, 2003; Beck & Lopes, 2007a, 2007b; Herwig & Böhles, 2003; McKenzie & Curle, 2012).

After the shock of the diagnosis and the subsequent necessity for the entire family system to learn to deal emotionally with the diagnosis and prognosis, there is usually a difficult phase of adaptation to restrictions in the conduct of life due to the treatment regime. There are also financial burdens (Mader et al., 2017b; Topf, 2000), such as additional costs for transportation to the clinic, parents' hotel accommodation when the child is hospitalized, or the cost of a parent giving up work or work hours, and additional expenses for the child's medical care not covered by health insurance.

There are frequently changes and serious tensions in the parents' relationship (feelings of guilt concerning the disease, or psychological burdens such as threat to parents' self-esteem, depression, mental and physical indisposition, disturbed sleep, and loneliness) (Forinder & Lindahl Norberg, 2010; Kohlsdorf & Costa Junior, 2012).

The chronic stress, due to the high demands of care and treatment as well as organizational problems (e.g., care of siblings), leads to exhaustion in caregiving family members (see Schröder, Lilienthal, Schreiber-Gollwitzer, & Griessmeier, 2008). Taking care of the child with cancer in the in-patient phase of treatment means that at least one parent must always be at the hospital. The needs of the child with chronic illness thus affect and shape family life (Kohlsdorf & Costa Junior, 2012; Warschburger & Petermann, 2002). Family members' psychosocial burden can be as serious as the burden of the patient with cancer, and in the first phase of the cancer diagnosis, they need professional help (Künzler & Zwahlen, 2012). Feelings of loneliness and uncertainty about the future and the fear of recurrence remain within the parents, a situation summarized by McKenzie and Curle (2012, p. 1) as "the end of treatment is not the end."

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Necessity of providing Social Counseling Services

Clinical social works' function lies in working on the social dimension of health and illness (Sommerfeld, Dällenbach, Rügger, & Hollenstein, 2016). For social work in oncology, it not only addresses the sick person but all those close to him/her (partners, children, parents, etc.) who need information, advice, and social support (Kohlsdorf & Costa Junior, 2012; Rösler, Walther, Schneider, & Adolph, 2016). From a systemic point of view, these others can even be part of the social dimension of the cancer and thus, contribute to the burden on the sick person, for example, through inadequate coping strategies.

Very broadly, (clinical) social work aims to improve people's life conditions and social integration. Its specific function is to handle crises involving problems arising in the dynamics of all kinds of life conduct systems (Sommerfeld et al., 2016). A life conduct system is comprised of the individual and his or her specific form of integration (position and interaction) in diverse social action systems (such as family, work, education, daily structure, and living/housing).

For the individual, the conduct of life goes along with tasks in managing life and dealing with different or variously caused threats to social integration. Studies have shown that a child's cancer is one such threat, and it can have an unfavorable effect on integration in different action systems. The accompanying social problems – understood here as the social dimension of the cancer – always seen in the family context (Kohlsdorf & Costa Junior, 2012; Muthny & Bengel, 2009) – are the result of the interplay of different areas of life. For this reason, a systemic perspective is effective with psychosocial interventions (Sommerfeld et al., 2016), and it makes sense to include an analysis of dynamics that cause and reinforce problems in the life conduct system when drawing up a social diagnosis. In clinical social work, social counseling is an important methodological instrument of such intervention (Hüttemann & Rügger, 2013). The planned case work in social counseling comprises the

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phases of social diagnosis, intervention, and evaluation. Social counseling services actively support and influence, in a planned manner, the subjective conduct of life of individuals in cases where life conduct can become socially problematic.

When social counseling succeeds, the result for the individual is, among other things, a stronger sense of coherence (Antonovsky, 1993) – a feeling of confidence that one's life and environments, inner and outer, are predictable, comprehensible, meaningful, and manageable. It also leads to an improvement or at least stabilization of the quality of life of families of a child with cancer (for similar results, see Diegelmann & Beyer, 2011; Kröger, 2005; Sommerfeld, Hollenstein, & Calzaferri, 2011).

Psychosocial Counseling for Families of Children with Cancer

Numerous studies are available on the effects of psychosocial interventions (mostly on the target dimension “quality of life”) with adult cancer patients or patients with chronic diseases (Guo et al., 2013; Heesook, Youn-Jung, Hyerang, & Yoonju, 2018; Raingruber, 2011; Soellner & Keller, 2007). Meta-analyses found strong indications that psychosocial interventions have small positive effects on emotional adjustment, functional adjustment, and treatment of disease-related symptoms in adult cancer patients, but the overall effect size of psychosocial counseling is moderated by several confounding factors including the duration of psychosocial intervention and quality of the relationship between patient and therapist (e.g., Rehse & Pukrop, 2003).

Overall, there is growing evidence that psychosocial interventions improve the well-being of cancer patients. Intervention studies have focused mostly on adults or children with cancer or patients with chronic diseases themselves who have received treatment.

Investigations focusing on the impact of social counseling on parents (of children with

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cancer) are rare or non-existent. Moreover, questions concerning the effects of different interventions as well as their long-term impact remain unresolved (Soellner & Keller, 2007).

Diagnostics in Social Work

Psychosocial support for parents and their children needs to be planned (Darcy et al., 2019). A fundamental element of intervention with social counseling is the use of diagnostic instruments (Dällenbach, Rügger, & Sommerfeld, 2013; Rügger, 2010). Diagnostic instruments are a fundamental prerequisite to developing feasible suggestions for appropriate services or necessary interventions (Rügger, 2010; Sommerfeld et al., 2016) and should be carried out as early as possible in the course of the disease so that existing burdens can be detected early and an aggravation of psychosocial problems can be prevented (Leitlinienprogramm Onkologie, 2014). Theoretically, it can be assumed that the better the case-specific social dimension and the associated problem dynamics are worked out and understood, the better an intervention can be planned and implemented which deals precisely with the social dimension and leads to sustainable improvement (Sommerfeld et al., 2016).

In scientific discourse in the field of social work, there is an active debate on the development of suitable concepts and methods for case analyses (Buttner, Gahleitner, Hochuli Freund, & Röh, 2018; Gahleitner, Hahn, & Glemser, 2012). Some empirical studies on diagnostics in social work are available in the English-language literature, especially with regard to quantitative research in the areas of clinical social work (Harkness, 2011; Haunberger, Rügger, & Baumgartner, 2019; Ishibashi, 2005) and child protection (e.g., Helm, 2011; Thomas & Holland, 2010). In contrast, in the German-language literature, only few empirical studies are available on diagnostics in social work in the area of public health (Gautschi & Rügger, 2012; Hanses, 2002; Hüttemann, 2008; Wyssen-Kaufmann, 2015) and child protection (Becker-Lenz, Gautschi, & Rügger, 2017; Rügger, 2017). However, there

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is no systematic compilation of diagnostic methods for clinical social work (Sommerfeld et al., 2016, p. 286). Furthermore, no empirical findings are available on the effects of the use of diagnostic instruments on the clients' life conduct or quality of life. Hanses (2000) was at least able to show that, with implementation of biographical diagnostics in vocational rehabilitation practice, there was positive change in the interaction order and working relationship between professionals and their clients in the diagnostic interview. Formative evaluation of the diagnostic instrument "descriptive system modeling (DSM)" indicates that it has been possible to recognize key elements of a life conduct system (see Gautschi & Rügger, 2012).

In summary, there is a broad consensus in the specialist discourse on the importance of social diagnostics for intervention, and that there now exists a large number of social diagnostic instruments but little empirical evidence of their effect within intervention (see also Sommerfeld et al., 2016).

However, it can be assumed that social diagnostic methods enable different diagnostic views and lead to different forms of help. So, we are interested in different effects in the clients' life conduct or quality as a result of social counseling based on different social diagnostic methods.

Research Questions

The following questions need to be noted and answered in this study.

1. What is the overall effect of social counseling on the following target dimensions: quality of life, psychosocial burden, and sense of coherence in parents of children with cancer, for parents with high and parents with low psychosocial burden?
2. How large are the effect sizes?
3. Do other variables (e.g., child's health status) moderate social counseling impact on the target dimensions?

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4. Do different types of social diagnostic methods in social counseling result in different effects on the target dimensions?

Methods

Design

To demonstrate the effectiveness of social counseling based on different social diagnostic methods, systematic trial and testing in experimental settings is required. To answer our research questions, we chose a quasi-experimental design, in the framework of a longitudinal prospective study with three measurement points to compare parent's psychosocial development in relation to social counseling based on different social diagnostic methods. Related to the state of research there exists no evidence so far of which effect size social counseling has. Because we do not have another data set or related study to compare, we specify the smallest effect size we consider relevant. Therefore, we expect medium effect sizes of $\eta^2 = .06$ for social counseling (Cohen, 1988), and calculated with a target sample size of 30 persons each for the intervention group and the control group. Figure 1 shows the pre-test–post-test control group design with follow-up (Fisher & Foreit, 2002, p. 50).

****Figure 1 about here

In our pre-test–post-test control group design, we made an initial measurement in the intervention and control group (O_1 and O_4 , respectively). In this special case, the intervention group received the program intervention X_1 (based on diagnostic method DSM, Sommerfeld et al., 2016, pp. 291–371). The control group was treated as usual with intervention X_2 (based on diagnostic method S-FIRST, Hošek, 2012). After the intervention period, we did a second measurement (O_2 and O_5 , respectively) 4–5 months after diagnosis. To measure the effects of social counseling based on different social diagnostic methods in the long run, we included a

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test interval after 6–12 months (O₃ and O₆). The third measurement point marked the end of intensive medical treatment and varied depending on the type of cancer diagnoses from 6–12 months. The duration between measurement times 1 and 3 can therefore vary in individual cases, which can also have an influence on the measured difference. Since there exists no recommendations for the intervals of the measurement points, we oriented ourselves toward comparable studies (Barrera et al., 2014; Darcy et al., 2019; McCarthy, Clarke, Vance, Ashley, Heath, & Anderson, 2009) and medical advice from the children's hospital that different types of cancer require different treatment times.

Participants

Sample. The population of this study comprised all parents ($N = 109$) whose children were diagnosed with cancer and treated in the pediatric oncology department in a children's hospital in Switzerland. All parents, who used the hospital's social counseling service between February 2014 and November 2016, were invited to participate in the study.

In the total sample, there were neutral non-responses and refusals. The absolute highest refusal rate occurred in survey wave one. Therefore, the following response rates (adjusted sample) per survey wave were achieved: 85% (survey wave one), 92% (survey wave two), and 98% (survey wave three). Despite the relatively low sample size, an exceptionally high response rate in all three waves provided a solid foundation of data and underscored the high level of parents' engagement. Furthermore, our strategy paid off in that a staff member of the children's hospital controlled the distribution of questionnaires and telephonic reminders. However, despite a high response rate and the extension of the survey period, we were unable to reach the target population of $n = 30$ per arm for various reasons. During the survey period, fewer cases were admitted to the hospital than expected; some patients only underwent surgery without using social services.

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Subsample. In a first step, we divided the population into two groups with the help of the S-FIRST screening instrument. A cut-off level (13-14) was calculated using the statistical part of S-FIRST (for details see Haunberger et al., 2019). On the basis of $N = 71$ cases (survey wave one), the screening divided the parents into a group with high psychosocial burden (56%, $n = 31$) and a group with low psychosocial burden (44%, $n = 40$).

In a second step, parents with high psychosocial burden were assigned randomly to either the intervention or the control group (see Figure 2). The intervention group (A) was counseled on the basis of the DSM; the control group (B) was counseled as usual (S-FIRST). Of the 40 parents with high psychosocial burden, 45% ($N = 18$) were randomly assigned to the control group and 55% ($N = 22$) to the intervention group, corrected by a slight oversampling of the intervention group. For ethical reasons, no group was completely without treatment. Therefore, group (C), with low psychosocial burden ($N = 31$), was also counseled as usual. In all three arms of the study, we controlled for the nature and frequency of social counseling and other moderating variables.

****Figure 2 about here

Characteristics of the sample. We describe the whole sample and present differences between intervention and control group in Table 1. The children suffering from cancer were on average six years old, the youngest child was one year old, the oldest child was 17 years old. Boys comprised $n=32$ of the sample and girls, the remaining $n=39$. The parents were on average 38 years old, the youngest parent was 22 years old, the oldest parent was 62 years old. As regards marital status, $n=56$ of the parents were married, while the remaining $n=14$ were unmarried ($n=4$), separated ($n=8$), widowed ($n=1$), or living in a registered partnership ($n=1$). Swiss or dual nationality comprised $n=47$ of the parents, while

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n=24 of the parents were from different foreign nations. 38 families have two children, n=15 one child, and n=14 three children; only one family had more than four children.

******Table 1 about here*

Instruments

To measure the effects of social counseling, initial target dimensions must be defined. The assessment of health-related quality of life is increasingly accepted in medicine (and other scientific disciplines) and has been acknowledged as an essential component in measuring therapy/counseling success (Bullinger, 2000; Garratt, Schmidt, & Fitzpatrick, 2002; Goldbeck, 2001).

Impact on Family Scale (IFS). The IFS is a self-report instrument designed to assess the well-being of families of children with chronic conditions and disabilities. We used the German version of the IFS (Stein & Riessman, 1980), translated and tested psychometrically. The IFS contains 33 items that describe social relationships and assess general negative impact on parents, concern for siblings, financial impact, problems in coping, and a total score (for details, see Ravens-Sieberer, Morfeld, Stein, Reissmann, Bullinger, & Thyen, 2001). The fully verbalized, four-point Likert scale runs from 1 (*fully correct*) to 4 (*not correct at all*). The IFS contains 33 Likert-scaled items and five dimensions. The internal consistency of the subscales, as measured by Cronbach's alpha, showed mostly satisfactory values (Daily and social burden $\alpha = .79$; Personal burden $\alpha = .66$; Financial burden $\alpha = .54$; Burden on siblings $\alpha = .79$; Difficulties in coping $\alpha = .50$; Total burden $\alpha = .71$). As far as the psychometric properties are concerned IFS revealed good reliability (internal consistency) and construct validity (Stein & Riessman, 1980).

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Munich List of Quality of Life Dimensions (MLDL). The MLDL measures satisfaction with several quality of life dimensions. The questionnaire contains 19 items that assess physical (health, physical and mental resilience, health care, disease management), psychological (well-being, self-esteem, recognition, relaxation), everyday life (job, finances, home, leisure, autonomy), and social life (marriage/partner, sex life, family, friends, social support) dimensions (for details, see von Steinbüchel, Bullinger, & Kirchberger, 1999). The only-at-the-endpoint-of-the-scale verbalized, 11-point response scale ranges from 0 (*dissatisfied*) to 10 (*satisfied*). The MLDL contains 19 eleven point-scaled items and four dimensions. The internal consistency of the subscales, as measured by Cronbach's alpha, showed mostly satisfactory values (Body $\alpha = .83$; Psyche $\alpha = .87$; Social life $\alpha = .77$; Everyday life $\alpha = .72$; Overall $\alpha = .89$). The MLDL revealed satisfying values for reliability and validity, it also indicated a good sensitivity (Steinbüchel et al., 1999).

Sense of Coherence Questionnaire (SOC-13). The SOC-13 measures the construct *sense of coherence*, developed within the framework of salutogenesis by Antonovsky (1993). The SOC-13 is the short form version of the instrument, with 13 seven-point-scaled items from 1 (very often) to seven (never) to assess the three dimensions comprehensibility, manageability, and meaningfulness (for details, see Schumann, Hapke, Meyer, Rumpf, & John, 2003). The internal consistency of the subscales, as measured by Cronbach's alpha, showed mostly satisfactory values (Meaningfulness $\alpha = .68$; Manageability $\alpha = .64$; Comprehensibility $\alpha = .60$). For ease of reading, the order of answers in the analyses have been revised; higher values mean fewer burden (IFS) and better manageability, comprehensibility, and meaningfulness (SOC-13). The SOC-13 scale seems to be a reliable, valid instrument measuring how people manage stressful situations and stay well (Eriksson & Lindstrom, 2005) (see Table 2).

*****Table 2 about here

The Experimental Condition

Social workers use various methods to prepare an optimal social diagnosis and then to advise their clients. In this quasi-experimental study, two social diagnostic methods were considered.

Social Diagnostic based on S-FIRST (control group). The social diagnosis instrument S-FIRST (Hošek, 2012) focused on the family resources. It captures an overview of the family situation at the start of counseling and aids assessment of the need for social work support. However, it does not allow a deeper understanding of the problems. Narrative information is gathered on family resources or lack of resources in the following areas: social support, housing, finances, work, parents' health, care of other family members, integration of the patient, mobility, insurance, monitorability of the happenings, and value systems. The social worker records details on the family situation and asks about possible matters of concern. The S-FIRST also includes a statistical part that serves as a standardized assessment of the burden situation and thus, acts as a screening instrument for consultancy needs. Social workers have been working with S-First for some time. The use of this social diagnostic method therefore corresponds to practice as usual.

Social Diagnostic Based on DSM (intervention group). The diagnosis method of descriptive system modeling (DSM) (Sommerfeld et al., 2016, pp. 291–371) is an expanded form of diagnosis, in that beyond assessing any lacking resources in the families, this systemic diagnostics focuses on the interplay of different areas of life conduct and action systems and on problem-causing and problem-aggravating dynamics in the life conduct system altogether. It identifies additional psychosocial (problem) dynamics in areas (family, work, and neighborhood) of life conduct.

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This provides well-founded starting points for service planning. For the exploration of the life conduct system, several elements of an existing diagnostic instrument are used. The social workers were trained in the use of these instruments before the start of their studies. Parallel to the first cases, supervision with a focus on the application of social diagnostic was also offered.

Moderating Variables. Because there are empirical indications that other variables can affect the measurement of intervention impact (Meyer & Mark, 1995; Rehse & Pukrop, 2003), we included moderating variables such as parents' sociodemographic variables, other forms of formal and informal help and support, child's health status (parents' subjective impression), and relationship between client and consultant. Furthermore, we monitored the intervention, including frequency and duration of social counseling, forms of intervention (person-, system-, or process-focused interventions), and type of intervention (material assistance, provision of information, networking, and psychosocial counseling).

Child health. In each survey wave, parents assessed the state of health of their child. The scale measures the child's physical and psychological well-being with eight items. The response scale ranges from (1) never to (5) ever. The internal consistency of the scale, as measured by Cronbach's alpha, showed a satisfactory value ($\alpha = .86$). For further analyses, we used the mean value over the three survey waves as a moderator variable of parents' quality of life, burden, and sense of coherence.

Duration and frequency of counseling. We collected monitoring data regarding how much time (in minutes) the social workers spent on each case and the number of consultations per case. We describe the whole sample and present differences between intervention and control groups in Table 3. The consultation time per case ranged from 30 minutes to 1,650 minutes, with $M = 437$ minutes. The consultation sessions with DSM took on average 469 minutes, while those with S-FIRST took on average of 525 minutes. We

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excluded three outliers. The number of consultations using DSM was $M = 8$, with a range running from one to 22; the number for those using S-FIRST was $M = 8$, with a range running from two to 29. A Mann–Whitney U-Test showed no significant differences ($p < .05$) between intervention and control group regarding the use of DSM or S-FIRST.

Specialist support within and outside the hospital. 52% of the mothers had contact with the social counseling service. Thirty-four percent of the parents used specialist support within the children’s hospital (which includes not only social counseling but also physiotherapy, psychological counseling, etc.) one to several times a week after diagnosis. The parents only rarely used specialist support outside the children’s hospital. A Mann–Whitney U-Test showed no significant differences ($p < .05$) between intervention and control group regarding the use of other specialist support within and outside the hospital.

Number of critical life events per case. The social worker collected critical life events per case that occurred during the counseling period. Critical life events include external familial events, recurrence of the disease, and other events. From these events, we formed a summative index. For 40% of the parents, no critical life events were mentioned, while for 54%, one to three critical life events were reported. A Mann–Whitney U-Test showed significant differences ($p < .05$) between intervention and control group regarding the number of critical life events. The control group mentioned more critical life events.

Assessment of implementation. Social workers also estimated, on a fully verbalized scale ranging from 1 (*totally disagree*) to 4 (*completely agree*), the extent to which implementation of the respective social diagnostic method had succeeded. To assess the quality of implementation of DSM, an extremely reliable scale ($\alpha = .956$) could be computed as well as for the assessment of the quality of implementation of the S-FIRST diagnostic method ($\alpha = .915$). A Mann–Whitney U-Test showed no significant differences ($p < .05$)

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between intervention and control group regarding the social workers' assessment of DSM and S-FIRST implementation.

******Table 3 about here*

Procedures

At the initial contact with the social counseling service, a hospital staff member did a screening with the parents, which divided them into a group with either high or low psychosocial burden.

All parents were given an informed consent in the form of a brochure, which included a clear appreciation and understanding of the facts, implications, and consequences of participation. After the decision to participate, parents received the questionnaire including an addressed and stamped return envelope, as well as a stuffed animal for children as an incentive. The distribution of the questionnaires, as well as the reminder, were carried out by a hospital staff member due to data protection. In order to consider the linguistic diversity of the parents, the questionnaire was translated into four main languages. The responsible Cantonal Ethics Committee did not express any concerns about the study (KEK-StV.-Nr. 07/13).

Data Analysis

Next, we examined the impact of social counseling, based on different social diagnostic methods, on the parents' quality of life, coping with burden, and sense of coherence (dependent variables). The dependent variables were measured three times: once immediately after diagnosis, once 4–5 months after diagnosis, and once 6–12 months after the end of intensive medical treatment. Repeated analysis of covariance (ANCOVA) measures

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considered the covariates health status of the child, the assessment of implementation of social diagnostic, parents' gender, and the number of critical life events. We computed the analyses with the statistics program SPSS 24.

Before using the ANCOVA, the normal distribution of each dependent variable was tested with the Kolmogorov–Smirnov test. Most of the dependent variables were almost normally distributed, with only a few falling below $p < .05$. The ANCOVA is fairly robust, however, when faced with deviations from the normal distribution (Harwell, Rubinstein, Hayes, & Olds, 1992; Lix, Keselman, & Keselman, 1996), Mauchly's test for sphericity was performed; and when the conditions were not met, the Greenhouse–Geisser correction was used.

For each ANCOVA we report p-values and effect sizes (Sullivan & Feinn, 2012). According to Cohen (1988), effect sizes of $\eta^2 = .01$ to $.04$ are considered small, effect sizes of $\eta^2 = .06$ to $.11$ are considered medium, and effect sizes of $\eta^2 = .14$ to $.20$ are considered large.

Results

The design allows us first to calculate a pre–post comparison without a control group. For this, we look at the subsample of parents only treated with S-FIRST. The subsample includes parents with low and high psychosocial burden (Group C and B in Figure 2). We treated burdened groups as covariate.

Impact of Social Counseling Based on S-FIRST on Parents with Psychosocial Burden

We have calculated own ANCOVAs for each moderating variable, which we cannot show for reasons of space, but to the results of which we refer to in the text.

Over time, the burden on parents with low psychosocial burden decreased significantly for most *dimensions of the IFS*: daily and social burden ($F = 12.320, p < .001$,

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$\eta^2 = .30$), personal burden ($F = 3.388, p < .05, \eta^2 = .11$), financial burden ($F = 4.250, p < .01, \eta^2 = .13$), burden on siblings ($F = 7.316, p < .05, \eta^2 = .26$), and total burden ($F = 7.109, p < .05, \eta^2 = .20$) (see Table 4). This effect also often varied along with the health of the sick child. The parents were less burdened with the child in a good state of health in terms of various dimensions. Likewise, this effect varied with the gender of the parents. Fathers were less burdened than mothers in terms of different dimensions such as daily and social burden ($F = 2.768, p < .10, \eta^2 = .09$) and personal burden ($F = 3.255, p < .05, \eta^2 = .11$) (ANCOVA not shown).

The decrease in the burden varied with the assessment of implementation of the social diagnostic method (i.e., the social workers estimate if the individual components of the social diagnostic method can be entirely applied). Contrary to the assumption that the burden decreases with the better assessment of implementation, the opposite was the case only for IFS daily and social burden ($F = 2.931, p < .069, \eta^2 = .16$) and IFS financial burden ($F = 2.925, p < .085, \eta^2 = .16$) (ANCOVA not shown). For other covariates like the duration and frequency of counseling, number of critical life events, support inside and outside the hospital, we found no significant differences.

Opposite tendencies were shown for the *quality of life measured by the MLDL*.

Parents with low psychosocial burden were more dissatisfied over time with their physical state of health ($F = 3.175, p < .05, \eta^2 = .10$), mental health ($F = 7.607, p < .001, \eta^2 = .21$), everyday life ($F = 5.657, p < .01, \eta^2 = .17$), and total ($F = 5.327, p < .05, \eta^2 = .16$). These effects partially varied with the health status of the sick child. The sicker the child was perceived as being, the more dissatisfied the parents were.

Satisfaction decreased as the implementation was better assessed only for the MLDL psyche ($F = 5.165, p < .05, \eta^2 = .26$) and everyday life ($F = 3.445, p < .05, \eta^2 = .19$) (ANCOVA not shown). For other covariates like the duration and frequency of counseling,

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number of critical life events, support inside and outside the hospital, we found no significant differences.

With regard to *the sense of coherence*, without control of covariates the situation is significantly less manageable ($F = 4.605, p < .01, \eta^2 = .14$), and less meaningful ($F = 3.834, p < .05, \eta^2 = .12$) for the group of parents with low psychosocial burden (ANCOVA not shown). These effects disappeared with the control of the burdened groups (see Table 4). For other covariates like the assessment of implementation, duration and frequency of counseling, number of critical life events, support inside and outside the hospital, we found no significant differences.

*****Table 4 about here

Impact of Social Counseling Based on S-FIRST or DSM on Parents with High Psychosocial Burden

Now, we calculate the pre–post comparison with the control group. For this we look only at the group with high psychosocial burden, which was randomly assigned to two different social diagnostic methods (Groups A and B in Figure 2). Again, we calculated own ANCOVAs for each moderating variable, which we cannot show for reasons of space, but to the results of which we refer to in the text.

Comparison of the initial level. First, it was controlled whether the intervention and control group had a comparable base line. For each dependent variable (IFS, MLDL, SOC-13), a univariate Analysis of Variance (ANOVA) with the experimental condition as an independent variable was calculated (ANOVA not shown). Before the intervention, IFS, MLDL and SOC-13 did not show significant differences ($p < .05$) between the intervention and control group. Respondents provided comparable information in these areas.

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Parents with a high psychosocial burden showed significantly more burden over time regarding daily and social burden ($F = 11.471, p < .05, \eta^2 = .36$). They showed significantly less burden in terms of personal ($F = 14.135, p < .05, \eta^2 = .41$) and financial burden ($F = 3.563, p < .05, \eta^2 = .151$), and the burden on siblings ($F = 20.687, p < .05, \eta^2 = .633$) (see Table 5 and Figure 3). These effects varied significantly together with the child's state of health; if their child was in good health, the parents were less burdened for example IFS daily and social burden ($F = 16.213, p < .05, \eta^2 = .45$).

Effects regarding social counseling based on different social diagnostic methods were seen only for the dimensions of financial burden and burden on siblings. Parents in the intervention group (DSM) tended to show less financial burden over time ($F = 2.847, p < .10, \eta^2 = .12$). Although the burden on siblings in the intervention group remained constant, it decreased for the control group (S-FIRST) ($F = 6.044, p < .01, \eta^2 = .34$). For other covariates like the quality of implementation, duration and frequency of counseling, number of critical life events, support inside and outside the hospital, we found no significant differences.

For the dimensions of quality of life, measured with the MLDL, no effects could be determined over the course of time for parents with a high psychosocial burden (see Table 5 and Figure 3). Only for the dimension of social life was a significant effect found that varied together with the health status of the child ($F = 3.425, p < .05, \eta^2 = .15$). Over time, parents with high psychosocial burden become more and more dissatisfied with their social life, strengthened by the child's poor health. For other covariates like the assessment of implementation, duration and frequency of counseling, number of critical life events, support inside and outside the hospital, we found no significant differences.

For the sense of coherence, without control of covariates, the situation became less manageable ($F = 3.925, p < .05, \eta^2 = .16$) and less meaningful ($F = 3.997, p < .05, \eta^2 = .04$) for parents with a high psychosocial burden over time (ANCOVA not shown). These effects

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disappear with the control of the experimental condition (see Table 5). For other covariates like the assessment of implementation, duration and frequency of counseling, number of critical life events, support inside and outside the hospital, we found no significant differences.

******Table 5 about here*

Discussion

This study examines if social counseling, based on different social diagnostic methods, affects the way in which parents deal with their child's cancer and if different social diagnostic methods result in different effects on parents' coping. We explored four questions in this study. Results of question one about the overall effect of social counseling on quality of life, psychosocial burden, and sense of coherence in parents of children with cancer are somewhat mixed. We found only two significant effects between intervention and control group. More differences that are significant can be seen between the groups with low and high psychosocial burden, however, due to the design of the study we cannot link those effects to the experimental condition. Regarding question two, the few effects that are shown are larger than expected. We found large effect sizes for the experimental conditions ($\eta^2 = .12$ for financial burden, $\eta^2 = .34$ for burden on siblings, see Table 5 and Figure 3). For question three, it can be stated that other variables moderate the development of the target dimensions and the impact of the experimental condition. In particular, the child's health status significantly influences parent's development of quality of life and burden. If the child was in good health, the parents were less burdened over time. This covariation also led to a different result in terms of the quality of life. If parents perceived the child's state of health as being worse, their satisfaction in several dimensions (mental and physical health, everyday life)

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decreased. Regarding question four, the experimental condition in the form of the variation of social diagnostic methods leads only to limited effects as can be seen in financial burden (reduction in intervention group with DSM) and the burden on siblings (reduction in control group with S-FIRST).

This study thus provides no evidence that social counseling brings about improvements in all target dimensions. The effects are rather selective, but concern some central dimensions – such as financial burden and the burden on siblings. The results are in line with findings from other studies that the overall effect is moderated by other factors, such as the child's state of health. The assumption, supported by the literature, that different methods of social diagnostics lead to different forms of help with different effects could not be confirmed in this study. At least, duration and frequency of counseling do not differ between intervention and control group. In terms of effects, differences between the two groups – as reported – are limited to the areas of financial burden and the burden on siblings. Reece (1994) refers to similar results. His study examined the effect of counseling on the quality of life of individuals with cancer and their family members. Counseling was not found to have an effect on the quality of life of these individuals, and interventions were not found to vary between intervention and control group.

There are some methodological limitations to discuss. The burden situation of the parents can be understood as a dynamic event in which the state of health of the child, in particular, plays a decisive role. If the health of the child is not better, even after intensive medical treatment, no reduction of the burden is to be expected. Thus, any variability in the measurement points (measurement point 3) might be of great importance for the reliability of the results. It must be considered that no objective data about the child's state of health could be used. It should also be critically noted that the dynamics of the life conduct system may not be adequately captured with three measurement points. A structured follow-up throughout the cancer

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trajectory could be necessary (Darcy et al., 2019). Kupst and Schulman (1988) showed with a prospective, six-year study on parental burden through the cancer of their child that the burden is the highest immediately after diagnosis and decreases after about a year.

As a further methodological limitation, it should be noted that the sample size of our study was rather small. Despite the extension of the measurement duration, it was not possible to reach the target sample size of 30 persons each for the intervention group and the control group. For these reasons, there might be some limitations in detecting small effects between groups (Type II error). It should be noted that the control group mentioned more critical life events than the intervention group, although no moderating influence of this factor was shown in the analyses. As the study does not include a control group for ethical reasons, the design is based on the comparison of two groups in which different social diagnostic methods have been used in social counseling. The results show little evidence that the use of DSM is more profitable. However, treatment integrity has been checked only to a limited extent (DSM), and assessments of implementation by social workers do not serve as a reliable measure of treatment integrity. It therefore can be stated that the potential of further developed social diagnostic method (DSM) could not be conclusively examined in this study. This requires further projects in other settings, as well as further analyses in which special attention should be paid to program integrity (Dane & Schneider, 1998). This study provides a solid basis for further investigation in the areas of social counseling and social diagnostics in cancer care.

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Characteristic	sample total	High psychosocial burden		Low psychosocial burden
		Intervent. group (DSM)	Control group (S-FIRST)	
Age of child	6 (M), 1 - 17 (range)	8 (M), 1 - 17 (range)	8 (M), 1 - 15 (range)	5 (M), 1 - 15 (range)
Gender of children	32 boys, 39 girls	13 boys, 9 girls	11 boys, 7 girls	8 boys, 23 girls
Age of parents	38 (M), 22 - 62 (range)	40 (M), 31 - 55 (range)	42 (M), 31 - 55 (range)	37 (M), 22 - 46 (range)
<i>Nationality of parents</i>				
Swiss	41	12	10	19
Dual-nationality	6	1	3	2
<i>Marital status of parents</i>				
Married	56	14	15	28
<i>Education of parents</i>				
Elementary school	6	6	3	3
Secondary school	28	5	10	13
College/university	22	10	5	15
Number of children	2 (M), 1 - 6 (range)	2 (M), 1 - 4 (range)	2 (M), 1 - 5 (range)	2 (M), 1 - 6 (range)
Note. N = 71, survey wave one		n = 22	n = 18	n = 31

Table 1. Sociodemographic characteristics of the sample

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	Intervention group (DSM)						Control group (S-FIRST)					
	Pre-test		Post-test		Follow-up-Test		Pre-test		Post-test		Follow-up-Test	
	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD
IFS												
Daily and social burden	2.74	0.63	2.55	0.67	2.70	0.57	2.98	0.34	2.40	0.42	2.48	0.48
Personal burden	2.31	0.81	2.71	0.56	2.79	0.63	2.38	0.77	2.63	0.35	2.74	0.48
Financial burden	2.37	0.70	2.65	0.71	2.98	0.66	2.81	0.67	2.63	0.73	2.41	0.42
Burden on siblings	2.29	0.68	2.65	0.89	2.65	0.85	2.07	0.62	2.70	0.62	2.80	0.58
Difficulties in coping	2.63	0.46	2.59	0.57	2.67	0.63	2.54	0.57	2.58	0.68	2.64	0.71
total burden	2.47	0.41	2.64	0.45	2.77	0.47	2.62	0.43	2.58	0.28	2.60	0.28
MLDL												
Body	6.54	2.03	6.67	1.89	6.49	2.36	6.35	1.72	6.28	1.61	6.02	1.59
Psyche	5.48	2.32	5.78	2.05	5.89	1.99	5.48	2.32	5.78	2.05	5.89	1.99
Social Life	6.35	2.10	6.46	1.93	6.40	2.57	6.98	1.51	6.85	1.95	6.29	2.10
Everyday Life	6.54	1.56	6.69	1.62	6.60	2.14	6.65	1.60	7.05	1.42	6.73	1.47
global	6.22	1.80	6.41	1.62	6.34	2.28	6.37	1.60	6.49	1.52	6.23	1.54
SOC-13												
Meaningfulness	4.96	1.03	4.69	0.80	4.58	1.02	4.83	1.17	4.93	0.68	4.71	1.12
Manageability	4.42	1.20	4.56	1.50	4.38	1.48	5.13	1.43	4.85	1.04	4.46	1.15
Comprehensibility	4.30	0.73	4.01	1.36	4.08	1.34	4.40	0.93	4.21	0.77	4.14	1.07

Table 2. Comparison of the measurement of dependent variables separated for intervention and control group
Notes. Intervention group Pre-test n = 22, Post-test n = 21, Follow-up-Test n = 15; Control group Pre-test n = 18, Post-test n = 15, Follow-up-Test n = 14

EFFECTS OF SOCIAL COUNSELING

Characteristic	sample total	High psychosocial burden		Low psychosocial burden
		Intervent. group (DSM)	Control group (S-FIRST)	
duration	437 (M), 30 - 1650 (range)	469 (M), 30 - 1570 (range)	525 (M), 80 - 1605 (range)	382 (M), 55 - 1600 (range)
frequency	8 (M), 1 - 36 (range)	8 (M), 1 - 22 (range)	8 (M), 2 - 29 (range)	7 (M), 2 - 36 (range)
Critical Life Event total	54% 1 - 3 critical life events	43% 1 - 3 critical life events	69% 1 - 3 critical life events	55% 1 - 3 critical life events
Childhealth_mean	2.6 (M)	2.47 (M)	2.89 (M)	2.53 (M)
Implementation DSM	2.55 (M)	2.72 (M)	*	*
Implementation S-FIRST	2.66 (M)	*	2.80 (M)	2.83 (M)
Supportinside_mean	34% once to several times a week	41% once to several times a week	39% once to several times a week	27% once to several times a week
Supportoutside_mean	18% once to several times a week	14% once to several times a week	33% once to several times a week	13% once to several times a week
N = 71, survey wave one		n = 22	n = 18	n = 31

Table 3. Description of moderating variables separated for intervention and control group

EFFECTS OF SOCIAL COUNSELING

dependent variable	Repeated Measures			Interaction between time of measurement and burdened groups			Interaction between time of measurement, burden groups and child's health status		
	F	p	η^2	F	p	η^2	F	p	η^2
IFS									
Daily and social burden	9.097	.000 ***	0.24	1.727	.187	0.06	12.320	.000 ***	0.30
Personal burden	7.701	.001 ***	0.21	0.777	.465	0.03	3.388	.041 *	0.11
Financial burden	4.672	.013 **	0.14	1.729	.187	0.06	4.250	.019 *	0.13
Burden on siblings	15.728	.000 ***	0.43	0.464	.632	0.02	7.316	.002 **	0.26
Difficulties in coping	3.567	.040 *	0.11	0.808	.451	0.03	3.896	.026	0.12
total burden	10.876	.000 ***	0.27	2.757	.072 †	0.09	7.109	.007 **	0.20
MLDL									
Body	2.144	.133	0.07	3.175	.049 *	0.10	3.019	.057 †	0.10
Psyche	7.322	.002 **	0.21	7.607	.001 **	0.21	4.019	.023 *	0.13
Social Life	0.589	.558	0.02	0.795	.457	0.03	0.909	.366	0.03
Everyday Life	5.150	.010 **	0.16	1.394	.256	0.05	5.657	.006 **	0.17
global	4.229	.025 *	0.13	2.178	.131	0.07	5.327	.007 **	0.16
SOC-13									
Meaningfulness	2.326	.107	0.08	0.284	.752	0.01	1.128	.331	0.04
Manageability	0.097	.908	0.00	0.562	.573	0.02	0.393	.677	0.01
Comprehensibility	0.068	.928	0.00	0.198	.821	0.01	0.401	.672	0.01

Table 4. Results for ANCOVA with repeated measures for all dependent variables in the subsample of parents treated with S-FIRST

Notes. † $p < .10$, * $p < .05$, ** $p < .01$, *** $p < .001$ (two-sided test); Pre-test $n = 49$, Post-test $n = 42$, Follow-up-Test $n = 41$

EFFECTS OF SOCIAL COUNSELING

dependent variable	Repeated measures			Interaction between time of measurement and experimental condition			Interaction between time of measurement, experimental condition and child's health status		
	F	p	η^2	F	p	η^2	F	p	η^2
IFS									
Daily and social burden	11.471	.000 ***	0.36	0.282	.756	.01	16.213	.000 ***	.45
Personal burden	14.135	.000 ***	0.41	2.248	.146	.10	12.012	.000 ***	.38
Financial burden 1)	3.563	.047 *	0.15	2.847	.069 †	.12	3.537	.039 *	.15
Burden on siblings	20.687	.000 ***	0.63	6.044	.007 **	.34	18.071	.000 ***	.60
Difficulties in coping	0.294	.736	0.01	0.255	.766	.01	0.573	.560	.03
total burden	17.575	.000 ***	0.47	0.883	.421	.04	17.059	.000 ***	.46
MLDL									
Body	0.124	.864	0.01	0.083	.920	.00	0.209	.812	.01
Psyche	2.014	.158	0.09	0.295	.746	.02	1.585	.222	.07
Social Life	2.554	.101	0.11	0.455	.638	.02	3.425	.052 *	.15
Everyday Life	1.104	.341	0.05	0.009	.982	.00	0.890	.403	.04
global	1.366	.266	0.06	0.009	.990	.00	1.342	.273	.06
SOC-13									
Meaningfulness	0.280	.751	0.01	0.194	.825	.01	0.370	.693	.02
Manageability	0.239	.788	0.01	0.838	.440	.04	0.008	.989	.00
Comprehensibility	1.110	.340	0.05	0.119	.888	.01	1.342	.305	.05

Table 5. Results for ANCOVA with repeated measures for all dependent variables in the subsample of parents with high psychosocial burden

Notes. * $p < .05$, ** $p < .01$, *** $p < .001$ (two-sided test); Intervention group Pre-test $n = 22$, Post-test $n = 21$, Follow-up-Test $n = 15$; Control group Pre-test $n = 18$, Post-test $n = 15$, Follow-up-Test $n = 14$; 1) adding child's health status, the significant effect of financial burden disappears.

EFFECTS OF SOCIAL COUNSELING

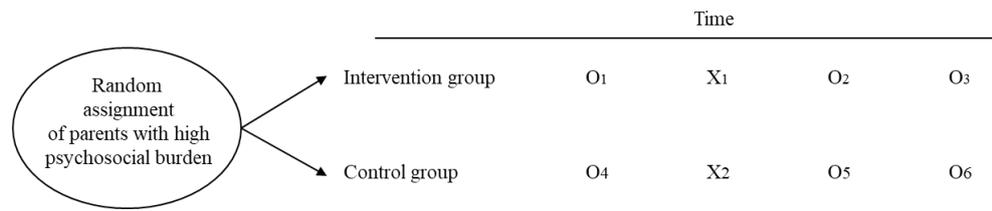


Figure 1. Pre-test–post-test control group design with follow-up

Note. O₁ & O₄ = measurement at the beginning; O₂ & O₅ = measurement 4–5 months after diagnosis; O₃ & O₆ = follow-up measurement 6–12 months after the end of intensive medical treatment; X₁ = DSM; X₂ = S-FIRST.

EFFECTS OF SOCIAL COUNSELING

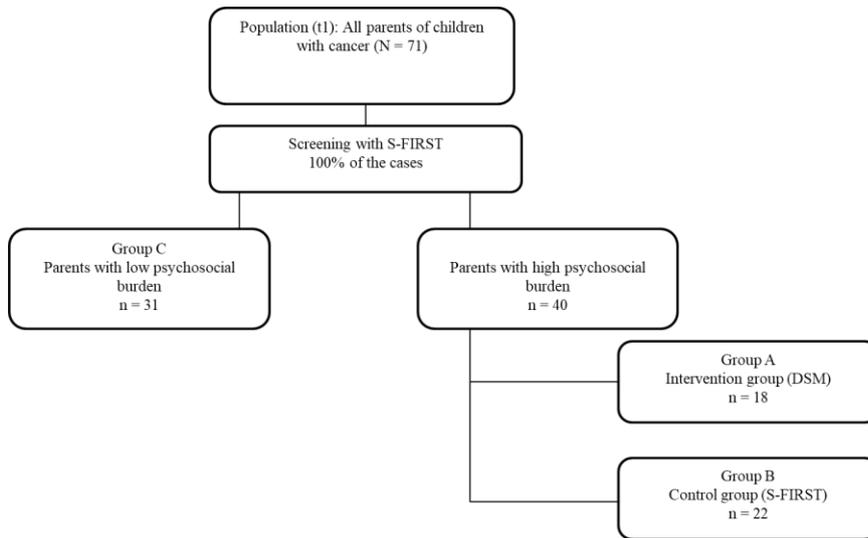


Figure 2. Population (number of cases, survey wave one)

EFFECTS OF SOCIAL COUNSELING

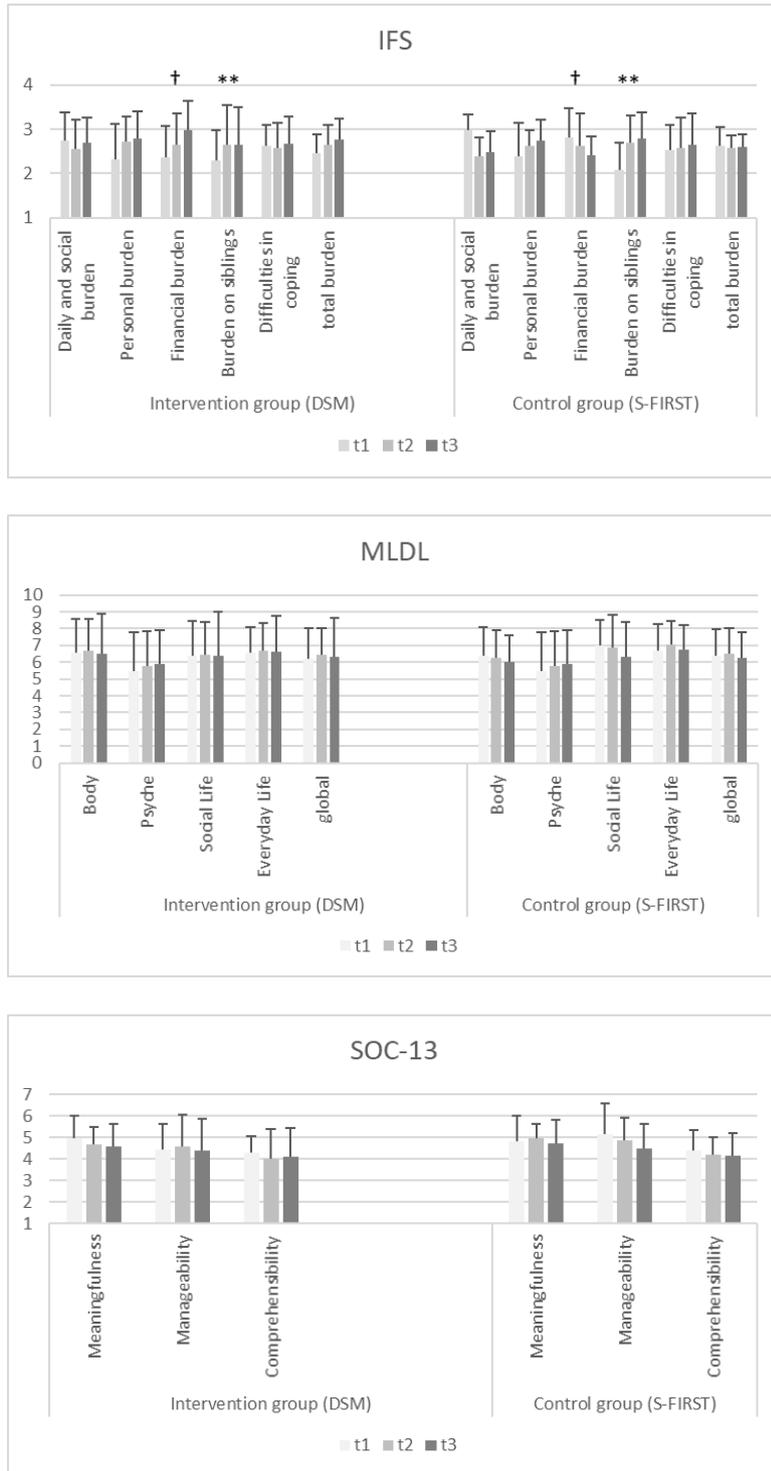


Figure 3. Development of the dependent variables IFS, MLDL, SOC-13 separated according to intervention and control group

Notes. †p < .10, *p < .05, **p < .01, ***p < .001 (two-sided test); Intervention group Pre-test (t1) n = 22, Post-test (t2) n = 21, Follow-up-Test (t3) n = 15; Control group Pre-test n = 18, Post-test n = 15, Follow-up-Test n = 14; The error bars represent the standard error.