Correlates of unmet needs and psychological distress in adolescent and young adults who have a parent diagnosed with cancer

Short title: Correlates of unmet needs and distress in AYA children of people with cancer

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Abstract

Objective. Young people who have a parent with cancer experience elevated levels of psychological distress and unmet needs. In this study we examined the associations between demographics, cancer variables, and family functioning; and levels of distress and unmet needs amongst young people who have a parent diagnosed with cancer.

Methods. Young people aged 12 -24 with a parent with cancer (n=255) completed the Offspring Cancer Needs Instrument (unmet needs), the Kessler-10 (distress), and the Family Relationship Index (family functioning), along with measures of demographics and cancer variables (such as: age, sex, time since cancer diagnosis). Variables associated with distress and unmet needs (including unmet need domains) were assessed using multiple linear regression.

Results. Being female and older, having more unmet cancer needs and poorer family functioning was associated with increased distress. Having a father with cancer, a shorter time since diagnosis, and poor family functioning were associated with increased unmet needs. Family conflict and expressiveness were particularly important components of family functioning. Having a parent relapse with cancer was also associated with unmet needs in the domains of practical assistance, ‘time out’, and support from other young people who have been through something similar.

Conclusions. Delineating factors associated with increased distress and unmet needs assists in identifying at risk young people allowing improved assessment and tailoring of support to improve the psychosocial outcomes of young people impacted by parental cancer.

Background

Adolescence and young adulthood (AYA[1]) is a period of considerable physical, emotional and mental development, when young people start to move away from their family and towards peers (1). In western countries the transition to adult responsibilities is often delayed, resulting in young adults maintaining stronger ties to the family for longer than previously (1, 2). Young people identify establishing a more equal relationship with their parent and becoming financially independent as important milestones in their progression to adulthood (1). Having a parent diagnosed with cancer during this period can disrupt this transition, as the young person may feel pressured to spend more time at home and not with their peers (3). Additionally, the responsibilty of care may shift from the parent being the primary carer to the child caring for their parent. Children may also delay moving out of home or seeking full time employment, thus impacting their transition to financial independence. These disruptions can cause considerable distress to the young person (4-7).

Young people who have a parent with cancer (offspring) often have elevated levels of distress (8, 9) and high levels of unmet needs (10). However, parents do not always recognise that their children are distressed (11). AYAs whose parents have cancer appear more affected; this age group reports higher anxiety and depression than both younger and older children (8). Additionally, the issues confronting this group are likely to differ from those impacting younger or older children due to their developmental stage, and thus warrant investigation. Recent research has focused on unmet needs amongst people impacted by cancer, as assessing unmet needs can be useful in the provision of more targeted services (12). Not all young people who have a parent with cancer require a psychological intervention, and therefore it is useful to identify risk factors for distress and unmet needs so that services can be appropriately directed (11).

Potential predictors of distress and unmet needs

Previous research on the psychological impact of parental cancer on children has focused primarily on younger children (13-15) with minimal attention to the concerns of young adults. Older adolescents have been found to be more distressed than younger adolescents when their parent has serious cancer (7); while other studies have found no effect of age amongst this age range (5, 16). Most studies have found more psychological issues in daughters of cancer patients (5, 8, 11, 14, 17, 18); however findings on the impact of the parent with cancer's sex have been mixed (see 5, 14 for a review).

While the stage of the parent's cancer does not appear to impact stress levels amongst offspring, shorter time since diagnosis (11) and lower projected 5 year survival rates (19) are both associated with greater concerns for offspring. Various features of the family may impact how well the child copes with the diagnosis; low levels of information exchanged between parents and their children about the cancer (20-22) and poorer family functioning (3, 9, 23), are associated with increased psychological problems for the offspring. Previous literature reviews have highlighted the complexity evident in the literature, (14, 24) some of which may be attributable to methodological factors including participant selection biases and measurement issues

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[1] The AYA age range has varying definitions, however for this paper it is defined as 12 to 24 years.

Study objectives

Given the above, in this study we examined the impact of demographic variables (offspring age, offspring and parental sex), cancer variables (time since cancer diagnosis, treatment stage, cancer relapse status), and family functioning variables (family functioning) on levels of distress and unmet needs on AYA offspring. While the impact of some of these variables on psychological issues has been examined before, their impact on AYAs as a group has not been considered, nor has their impact on levels of unmet needs.

Notwithstanding this, it was not unreasonable to hypothesise that AYA female offspring would have higher levels of distress, and that less time since the cancer diagnosis, relapsed cancer, and worse family functioning would be associated with higher levels of distress and unmet needs in AYAs. The impact of the remaining variables on distress and unmet needs were less certain and their inclusion is exploratory. The findings from this study will assist in identifying young people who are more vulnerable and allow tailoring of support services.

Method

Participants

The study was open to young people aged between 12 and 24 years who had a living parent or primary caregiver diagnosed with any type or stage of cancer within the previous five years. Data was collected between March 2009 and February 2011.

Procedure

Relevant institutional ethical clearance was obtained from the participating hospitals and CanTeen[2]. Online and paper versions of the questionnaire were developed. Participant information sheets were developed for both young people and their parents. Parental consent was obtained if the young person was under 18 years of age. The study was promoted at four Sydney hospitals using posters directing people to contact the research team. Additionally, notices were placed in two national cancer consumer newsletters and on national cancer consumer websites directing people to the online version of the survey. The paper version of the questionnaire, along with information sheets about the study and a stamped return envelope, were posted to young people who: (1) had recently (<12 months) joined CanTeen; (2) had ordered resources from CanTeen that were related to having a parent with cancer; or (3) belonged to another Australian national not-for-profit organisation that was piloting a support program for young people with a parent with cancer.

Materials

A self-report questionnaire assessing socio-demographic and medical information about the parent's cancer, unmet needs, psychological distress, family functioning, and parental communication was used. This is outlined in more detail below.

Independent variables

Socio-demographic and medical questions. The survey contained items asking for demographic information about the participant (e.g. age, sex), country of birth of the parent, and demographic and medical information about the parent diagnosed with

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[2] CanTeen is the Australian Organisation for young people living with cancer.

cancer and about their cancer (e.g. age, sex, type of cancer, time since diagnosis, cancer stage, relapse status).

Family Relationship Index (FRI; 25) The FRI contains 12 items on general family functioning, divided across three sub-scales: conflict, cohesion and expressiveness. Participants rate each item (e,g, "Family members really help and support me.") as true or false; total scores may range from 0-12, with higher scores indicating better family functioning. Internal consistency of the subscales ranges from 0.69 to 0.78 (26).

Dependent variables

Unmet needs – Offspring Cancer Needs Instrument (OCNI;12). The OCNI has 47 items clustered into seven domains: *Information about my parent's cancer*; *Family issues*; *Practical assistance*; '*Time out' and recreation*; *Dealing with feelings*; *Support from my friends;* and *Support from other young people*. Items are answered according to the sentence stem, "I currently need...," using four response options: 1 = *No need* ("I don't have any need for help with this issue"), 2 = *Low need* ("I have a low need for help with this issue"), 3 = *Moderate need* ("I have a moderate need for help with this issue"), and 4 = *Strong need* ("I have a strong need for help with this issue"). The OCNI has good psychometric properties with domain internal consistencies ranging from 0.89 to 0.96, and an overall test-retest reliability of 0.73. Mean scores for each item in the OCNI are presented in the paper validating the OCNI (12). Domain scores are calculated as the sum of the items in each sub-scale, and a total score as the sum of all of the items, where higher scores indicate greater need.

A half-mean imputation rule was used for missing items in the OCNI scale: if half or more of the items of the domain were completed for an individual, the missing items were replaced by the mean of the domain to which the item belonged.

Kessler 10 (K10; 27). The K10 is a 10 item measure widely used to measure psychological distress with excellent internal consistency ($\alpha = 0.93$). Although it was designed for use with adults, it has been previously used with Australians aged 16-24 (28) and has been validated in Hong Kong with people as young as 12 years ($\alpha = 0.93$; 29). Participants reflect on how they have been feeling over the last four weeks and respond using a 5 point scale (1=Never and 5 = All the time). Total scores can range between 10 and 50, with higher scores reflecting greater distress. In a large national study it was found that 9% of young Australians (16-24 years) had distress in the high or very high bands, that is 30 or above (28).

Statistical analyses

Frequencies and percentages of categorical independent variables were calculated, and means and standard deviations of continuous independent and dependent variables were calculated.

Predictors of distress and unmet needs were assessed by hierarchical multiple linear regression. We fitted nine models, with distress and total unmet needs and each domain of the unmet needs as the dependent variables and independent variables determined from our knowledge of needs and distress in young people. The first level of the hierarchical regression included age and sex (parent and offspring); the second level included the three FRI subscales; and the third level included all cancer related variables. For the model predicting distress, the total OCNI score was also included as a predictor[3]. All analyses were performed in SPSS version 22 (30)and statistical significance was set at 0.05.

Results

Participants

In total, 282 offspring responded, however 27 were excluded because they did not meet the eligibility criteria (i.e. were outside the age range or their parent was diagnosed more than 5 years earlier) , leaving a total eligible sample of 255. The participants ranged in age from 12 to 24 years, with time since diagnosis from just diagnosed to 5 years since diagnosis. Participants came from every state in Australia, with the proportions representative of the population distribution. See Table 1 for further demographic details.

[Insert Table 1 about here.]

Independent variable descriptives

Scores on FRI subscales range from 0 to 4 and are as follows: FRI-Cohesion, *M* = 2.7 (*SD* = 1.1), FRI-Conflict (reverse scored to calculate FRI-total), *M* = 1.55 (*SD* = 1.3), and FRI-Expressiveness, *M* = 1.8 (*SD* = 1.1). The FRI-total results are: *M* = 7.0 (*SD* = 2.7), where higher scores indicate better family functioning.

Dependent variable descriptives

Mean and standard deviations for the OCNI and K10 are presented in Table 2. The K10 mean (25.23) is high when compared with normative results which found 9% score above 22 (28).

[Insert Table 2 about here.]

Regression analyses

The results of the multiple regression analyses for each sub-scale and the total of the unmet needs measure (OCNI) and distress, are shown in Table 2. All models were significant overall.

Higher scores on the Information Domain (range: 9-28 SD=8.01) were associated with higher levels of family conflict and cohesion, less time since diagnosis and lower levels of family expressiveness. Being one point higher on FRI-conflict is associated with being 1.22 points higher on this Domain, being one point higher on FRI-cohesion is associated with being 1.37 points higher, and being one point higher on FRI-expressiveness was associated with being 1.66 points lower. A 12 month increase in time since diagnosis resulted in being 0.96 points higher on the Information Domain.

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[3] We expected the unmet needs to be too highly inter-correlated to be included as predictors in the same model, so included only the total score.

Higher scores on the Family Issues Domain (range: 4-16, SD=4.00) were associated with having a father rather than a mother diagnosed with cancer and lower levels of family expressiveness. Having a father diagnosed was associated with being 1.36 points higher on this Domain and a one point increase on FRI-expressiveness resulted in being 0.79 points lower.

Higher scores on the Practical Assistance Domain (range: 7-28, SD=5.32) were associated with lower levels of family expressiveness and less time since diagnosis, the cancer having relapsed and higher levels of family conflict. Being one point higher on FRI-Conflict is associated with being 0.53 points higher on this Domain and being one point higher on FRI-expressiveness resulted in being 0.91 points lower. Not having relapsed resulted in being 2.14 lower points on this Domain and a 12 month increase in time since diagnosis resulted in being 0.48 points lower.

Higher scores on the ‘Time out’ and Recreation Domain (range: 5-20, SD=4.80) were associated with lower levels of family expressiveness and the cancer having relapsed. Being one point higher on FRI-expressiveness was associated with being 1.01 points lower on this Domain and the cancer having relapsed was associated with being 1.91 points higher.

Higher scores on the Feelings Domain (range: 13-52, SD=11.02) were associated with having a father rather than a mother diagnosed with cancer, having the cancer relapse, and lower levels of family expressiveness. Having a father diagnosed was associated with being 4.29 points higher on this Domain, a 12 month increase in time since diagnosis was associated with being 1.08 points lower and being one point higher on FRI-Expressiveness was associated with being 2.54 points lower.

Higher scores on the Support from Friends Domain (range:4-16, SD=3.96) were associated with having a father rather than a mother diagnosed with cancer, less time since diagnosis, greater family conflict and less family expressiveness. Having a father diagnosed resulted in being 1.50 points higher on this Domain and an increase of 12 months in time since diagnosis resulted in being 0.36 points lower. Being one point higher on FRI-conflict was associated with being 0.48 points higher on this Domain and being one point higher on FRI-expressiveness was associated with being 0.99 points lower.

Higher scores on the Support from Other Young People (OYP) Domain (range: 5-20, SD=4.83) were associated with being younger, the cancer having relapsed, less time since diagnosis, greater family conflict and less family expressiveness. A five year increase in the offspring’s age was associated with being 1.15 points lower on this Domain, having relapsed was associated with being 1.48 points higher on this and an increase of 12 months in time since diagnosis was associated with being 0.60 points lower. Being one point higher in FRI-Conflict is associated with 0.53 higher on this

Domain and being one point higher in FRI-Expressiveness was associated with a 1.48 points lower.

Higher scores on Total Unmet Needs (OCNI; range: 47-188, SD=33.89) were associated with having a father rather than a mother diagnosed with cancer, less time since diagnosis, higher levels of family conflict and lower levels of family expressiveness. Having a father diagnosed with cancer was associated with being 10.36 points higher on the OCNI and an increase of 12 months in time since diagnosis was associated with being 3.84 points lower. Being one point higher on FRI-Conflict was associated with being 4.78 points higher on the OCNI and being one point higher on FRI-Expressiveness was associated with being 8.64 points lower.

Higher scores on the distress measure (K10; range: 10-50, SD=9.82) were associated with the offspring being female and older, higher scores on the OCNI-total, higher levels of family conflict and lower levels of family expressiveness. The offspring being female was associated with being 3.01 points higher on the K10 and being 5 years older was associated with being 2.95 points higher. Being one point higher on FRI-Conflict was associated with being 1.00 point higher on the K10 and being one point higher on FRI-Expressiveness was associated with being 1.17 points lower.

Discussion

This study provides important information on the factors impacting psychological distress and unmet needs amongst AYA offspring. Variables associated with greater distress were being a daughter (rather than a son), the AYA being older and high levels of unmet needs associated with having a parent with cancer. Variables associated with having high unmet needs for the combined measure (OCNI) were having a father (rather than a mother) diagnosed with cancer and a shorter time since the cancer diagnosis. , High levels of family conflict, low levels of family expressiveness,were associated with both higher levels of distress and greater unmet need. While the pattern of results varies for each OCNI domain, having a father diagnosed with cancer, high family conflict and low family expressiveness, cancer relapse and a shorter time since diagnosis were all commonly associated with higher levels of unmet need associated with different domains.

Modelling results

The results for offspring sex are consistent with past research (5, 8, 11, 14, 17, 18), as well as research that finds women tend to report more distress than men in general (31). The results also support the concept that distress increases with age amongst offspring within the AYA age range (7); with increasing age young people are likely to have a greater understanding of the consequences of a cancer diagnosis and may also take on additional family responsibilities. Results here demonstrate this pattern continuing into young adulthood.

Previous research on the impact of the sex of the parent with cancer on their children has had mixed results; in this study it was found that distress and unmet needs were higher when the father had cancer, rather than the mother. Research on distress levels amongst couples where one has cancer has found that females have higher levels of distress regardless of whether they are the patient or the caregiver, whereas males report higher levels of distress when they are the patient (32, 33). Additionally, a meta-analysis of role and sex effects in such couples has concluded that females experience more distress than males, regardless of which partner is ill (34).Thus when the father has cancer the cumulative levels of distress in the family would be higher, increasing the potential for distress amongst the children. There is also some evidence that fathers with cancer experience a transition in identity from a ‘strong working man’ to a ‘weak, sick person at home’ (35), negatively impacting the entire family. Higher unmet needs were reported on the OCNI domains associated with family issues (e.g. openness), feelings (e.g. coping with stress, feeling frustrated and angry) and support from friends (e.g. understanding from friends) when the parent with cancer was male. This suggests that family dynamics are impacted when the father has cancer, and that the offspring turns to friends outside the family for support.

Relapse status and time since diagnosis impacted unmet needs amongst AYA offspring. This is consistent with the impact of distress on the children of cancer patients following relapse found here, as AYA offspring often take on carer responsibilities. Additionally, it has been found that patients have more problems adjusting to a relapse than the original diagnosis (36) and that carers (particularly females) have greater fear of recurrence than patients (33, 37). Having relapsed was also associated with higher scores on unmet needs domains associated with practical assistance (e.g. assistance with jobs or chores around the house), ‘time out’ and recreation (e.g. to be able to have fun), and support from OYP (e.g. to feel supported by peers who have a similar experience with cancer). This reflects the additional burden on the household following relapse and the need for the young person to have time away from it, and support from those who have had similar experiences. As the time since diagnosis increases, young people have less need for support in those areas as well as less need for help coping with their feelings and from their friends.

Family functioning also had a significant impact on both levels of distress and unmet needs, with better family functioning resulting in decreased distress and unmet needs. This is particulary evident for the subscales associated with expressiveness and conflict. This is consistent with past research which found that better family functioning is beneficial to adolescents who have a parent with cancer (3, 38). The one unusual finding is that in families with high levels of cohesion (e.g. togetherness and support) there are higher unmet needs associated with information. This suggests that very cohesive families may not appreciate the high levels of information that AYA offspring need (10) and may inhibit AYAs asking for it. The results of the current study indicate that the importance of family functioning extends for offspring who are young adults as well, reinforcing the concept that young adults are still embedded in the family.

Consistent with previous research (10, 12), the close relationship between levels of distress and unmet needs is apparent in this study, with higher levels of unmet needs being associated with higher levels of distress. This can be seen in this study to be present despite the expected impact of poor family functioning and being female on distress levels. Of interest, when the OCNI is included in the model, there is no significant impact associated with any of the cancer variables, indicating that concerns associated with these variables are captured by the OCNI.

Limitations and future research

There are some potential limitations associated with the representativeness of the sample. Study participants were not entirely reflective of the cultural diversity of the general Australian population and future studies could be more deliberate in their cultural inclusion.

Approximately half of the participants were recent members of a support organisation for young people who have a parent with cancer, however their mean time since joining was less than three months. As such, the effect of membership was likely to be minimal. Additionally, previous evidence suggest that there are no differences between members and non-members in terms of their levels of distress or unmet needs (12, 39). Furthermore, it is possible that some participants came from the same family, although we do not have data to substantiate this.

Promotion of this study was general and not purposively targeted towards known AYA offspring. Assessment of response rate and reasons for declining was therefore not possible. This may limit the generalisabilty of results as those choosing to participate may have had higher unmet needs and distress. Differences in independent variables associated with levels of unmet need or distress are unlikely, though this could warrant further exploration.

As family functioning, particularly expressiveness (communication) and conflict, has been found to impact on the distress and unmet needs of AYAs who have a parent with cancer, intervention studies that focus on the family and/or aim to improve family functioning would be valuable. The impact of the sex of the parent who has cancer on offspring distress is not consistent between studies and several explanations have been proposed. It would be beneficial to explore this further to identify underlying causes of these differences.

Implications and conclusions

Examination of the associations between demographic, cancer and family functioning variables, and levels of distress and unmet needs in AYAs who have a parent with cancer, can help to identify which young people are at greater risk of distress or elevated levels of unmet needs. Those who are female or older, have their father diagnosed with cancer, have a parent who is recently diagnosed or has relapsed, or come from a family with poor family functioning, should be considered for assessment and possible intervention.

Understanding the role of these variables can help to identify young people who have a greater need of support services and greater risk of developing more serious psychological problems Used in conjunction with the OCNI to identify areas of specific need and a measure of psychological distress, it provides clinically useful information to more comprehensively support young people impacted by parental cancer.

Table 1.

Young person and parent demographics including cancer variables (*N*=255).

	Frequency (%)	M (*SD*)
Young person		
Age at time of survey (years)		16.1 (3.2)
Age when parent diagnosed (years)		14.0 (3.6)
Sex		
Male	66 (25.9)	
Males (12-17 years)	48 (18.9)	
Males (18-24 years)	18 (7.1)	
Female	189 (74.1)	
Females (12-17 years)	145 (56.9)	
Females (18-24 years)	44 (17.3)	
Country of birth		
Australia	238 (93.3)	
United Kingdom	5 (2.0)	
New Zealand	4 (1.6)	
Other	8 (3.1)	
Aboriginal and Torres Strait Islander	8 (3.1)	
CanTeen membership		
Member of CanTeen	127 (49.8)	
Length of membership (months)		2.5 (3.9)
Parent diagnosed with cancer		
Sex		
Male	79 (31.0)	
Female	173 (67.8)	
Other (e.g. guardian)	3 (1.2)	
Country where mother born		
Australia	199 (78.0)	
United Kingdom	22 (8.6)	
Rest of Europe	12 (4.7)	
Asia-Pacific	9 (3.5)	
New Zealand	8 (3.1)	
North America	4 (1.6)	
Missing	1 (0.4)	
Country where father born		
Australia	193 (75.7)	
United Kingdom	23 (9.0)	
New Zealand	11 (4.3)	
Rest of Europe	10 (3.9)	
North America	7 (2.7)	
Asia-Pacific	5 (2.0)	
Missing	6 (2.3)	
Cancer types[a]		
Breast	108 (42.4)	
Digestive	43 (16.9)	
Leukaemia	21 (8.2)	
Lung	19 (7.4)	
Bone/soft tissue	18 (7.0)	

Head & neck	15 (5.9)	
Reproductive	15 (5.9)	
Non-Hodgkin’s	11 (4.3)	
Brain	10 (3.9)	
Liver	8 (3.1)	
Other	27 (10.6)	
Time since diagnosis (months)		16.7 (16.3)
Treatment stage		
Recently diagnosed	13 (5.1)	
On treatment	161 (63.1)	
Finished treatment	66 (25.9)	
Unsure/ Other/ Missing	15 (5.9)	
Relapse status		
Never relapsed	179 (70.2)	
Has relapsed	71 (27.8)	
Missing	5 (2.0)	

[a] Some people had more than one type of cancer.

Table 2. Predictors of unmet needs and distress. Measure means (SD), model R (p) and regression coefficients and 95% confidence intervals are shown (bold=significant).

Dependent Variable (range)	Information (9-28)		Family issues (4-16)		Practical assistance (7-28)		'Time out' & recreation (5-20)		Feelings (13-52)		Support from friends (4-16)		Support from OYP (5-20)		Total OCNI (47-188)		K10 (10-50)	
Mean (SD)	23.39	(8.01)	9.81	(4.00)	14.40	(5.32)	12.34	(4.80)	30.20	(11.02)	10.00	(3.96)	12.10	(4.83)	112.24	(33.89)	25.23	(9.82)
Model (R, p)	R **.36**	p **.000**	R **.34**	p **.001**	R **.42**	p **.000**	R **.46**	p **.000**	R **.50**	p **.000**	R **.48**	p **.000**	R **.40**	p **.000**	R **.48**	p **.000**	R **.67**	p **.000**
Predictors	B	(±95%CI)	B	(±95%CI)	B	(±95%CI)	B	(±95%CI)	B	(±95%CI)	B	(±95%CI)	B	(±95%CI)	B	(±95%CI)	B	(±95%CI)
Offspring sex (ref=female)	1.76	-0.51, 4.03	1.25	0.10, 2.39	-1.08	-2.54, 0.39	-0.21	-1.50, 1.10	-1.52	-4.43, 1.38	-0.47	-1.53, 0.59	-0.23	-1.58, 1.12	-0.08	-9.15, 8.99	**-3.01**	**-5.24, -0.79**
Unwell parent sex (ref=mother)	1.34	-0.70, 3.37	**1.36**	**0.33, 2.38**	0.36	-0.95, 1.67	0.63	-0.53, 1.78	**4.29**	**1.70, 6.88**	**1.50**	**0.55, 2.45**	1.06	-0.15, 2.26	**10.36**	**2.23, 18.49**	1.84	-0.19, 3.86
Age Child (years)	0.16	-0.16, 0.48	-0.10	-0.27, 0.06	-0.03	-0.23, 0.18	-0.16	-0.35, 0.02	0.12	-0.29, 0.53	-0.11	-0.26, 0.04	**-0.23**	**-0.42, -0.04**	-0.29	-1.58, 0.99	**0.59**	**0.27, 0.90**
FRI-Conflict (0-4)	**1.22**	**0.45, 1.99**	0.32	-0.07, 0.71	**0.53**	**0.04, 1.03**	0.41	-0.03, 0.85	**1.42**	**0.44, 2.41**	**0.48**	**0.12, 0.84**	**0.53**	**0.08, 0.99**	**4.78**	**1.71, 7.85**	**1.00**	**0.23, 1.77**
FRI-Cohesion (0-4)	**1.37**	**0.34, 2.39**	0.31	-0.20, 0.83	-0.14	-0.80, 0.53	-0.25	-0.83, 0.34	-0.12	-1.42, 1.19	0.27	-0.21, 0.75	0.32	-0.29, 0.92	1.91	-2.20, 6.02	-0.38	-1.39, 0.63
FRI-Expressiveness (0-4)	**-1.66**	**-2.52, -0.81**	**-0.79**	**-1.22, -0.36**	**-0.91**	**-1.46, -0.36**	**-1.01**	**-1.50, -0.53**	**-2.54**	**-3.63, -1.46**	**-0.99**	**-1.39 -0.59**	**-0.72**	**-1.22, -0.22**	**-8.64**	**-12.05, -5.24**	**-1.17**	**-2.05, -0.29**
Relapse (Ref=relapsed)	-0.42	-2.71, 1.88	-0.28	-1.44, 0.88	**-2.14**	**-3.62, -0.66**	**-1.91**	**-3.22, -0.60**	-2.29	-5.22, 0.63	-0.60	-1.66, 0.47	**-1.48**	**-2.84, -0.12**	-8.98	-18.17, 0.21	-1.19	-3.47, 1.07
Time since diagnosis (months)	**-0.08**	**-0.15, -0.02**	-0.01	-0.04, 0.03	**-0.04**	**-0.08, -0.001**	-0.03	-0.06, 0.01	**-0.09**	**-.17, -0.01**	**-0.03**	**-0.06, -0.002**	**-0.05**	**-0.09, -0.01**	**-0.32**	**-0.57, -0.07**	-0.05	-0.11, 0.02
OCNI-Total (47-188)																	**0.12**	**0.09, 0.15**

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CONFLICT OF INTEREST

None of the authors have any conflict of interest. The corresponding author has full control of all primary data and agrees to allow the journal to review the data if requested.

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