

RESEARCH PAPER

Coeliac disease: the association between quality of life and social support network participation

A. R. Lee,¹ R. Wolf,¹ I. Contento,¹ H. Verdelli² & P. H. R. Green³

¹Department of Health and Behavior Studies, Teachers College, Columbia University, New York, NY, USA

²Global Mental Health Lab, Teachers College, Columbia University, New York, NY, USA

³Coeliac Disease Center at Columbia University, New York, NY, USA

Keywords

coeliac disease, public health.

Correspondence

A. R. Lee, 1050 Wall Street West #370,
Lyndhurst, NJ 07071, USA.
Tel.: +1 201 355 8470
Fax: +1 201 355 8624
E-mail: anne.lee@drschar.com

How to cite this article

Lee A.R., Wolf R., Contento I., Verdelli H., Green P.H.R. (2015) Coeliac disease: the association between quality of life and social support network participation. *J Hum Nutr Diet.*
doi: 10.1111/jhn.12319

Abstract

Background: There is little information available on the use of social support systems for patients with coeliac disease (CD). We performed a cross-sectional study aiming to examine the association between participation in different types of social support networks and quality of life (QOL) in adults with CD.

Methods: A survey including a validated CD specific QOL instrument was administered online and in-person to adults with CD who were following a gluten-free diet. Participation in social support networks (type, frequency and duration) were assessed.

Results: Among the 2138 participants, overall QOL scores were high, averaging 68.9 out of 100. Significant differences in QOL scores were found for age, length of time since diagnosis and level of education. Most (58%) reported using no social support networks. Of the 42% reporting use of social support networks (online 17.9%, face-to-face 10.8% or both 12.8%), QOL scores were higher for those individuals who used only face-to-face social support compared to only online support (72.6 versus 66.7; $P < 0.0001$). A longer duration of face-to-face social support use was associated with higher QOL scores ($P < 0.0005$). By contrast, a longer duration and increased frequency of online social support use was associated with lower QOL scores ($P < 0.03$).

Conclusions: Participation in face-to-face social support networks is associated with greater QOL scores compared to online social support networks. These findings have potential implications for the management of individuals with CD. Emphasis on face-to-face support may improve long-term QOL and patient outcomes.

Introduction

Coeliac disease (CD) is a genetically-mediated autoimmune disorder triggered by the consumption of the protein gluten⁽¹⁾. Gluten is the term for the proteins found in common cereal grains, wheat, rye and barley. Long-term complications as a result of malabsorption and

intestinal damage can lead to osteoporosis⁽²⁾, iron-deficient anaemia⁽³⁾ infertility⁽⁴⁾ and a variety of other health problems⁽⁵⁾, including gastrointestinal cancers⁽⁶⁾.

Prior studies have shown that the restrictions of the gluten-free diet (GFD) (the only treatment for CD) have a major impact on an individual's quality of life (QOL)^(7–10). However, the overall QOL of an individual

with CD initially improves with diagnosis and the initiation of the diet^(9,11). The chronic nature of the disease, together with the persistent vigilance needed to maintain a GFD, have been reported as major factors in the diminished QOL scores in this population^(7,12). Physical symptoms, the high cost of gluten-free foods and the emotional strain of social interactions within a rigid dietary regimen are frequent concerns for individuals with CD⁽¹³⁾. In addition, the social nature of a contemporary lifestyle, which may include dining out with friends, work-place functions and a reliance on convenience meals, may increase the burden of the diet and the impact on QOL^(7,9,10). Referral to and involvement with a coeliac support groups was recommended as part of the management of the disease in recent studies^(14,15), as well as by the NIH Consensus Development Conference on Coeliac Disease, 2004⁽¹⁶⁾.

Participation in social support groups can improve QOL for individuals with chronic diseases⁽¹⁷⁾. Traditional face-to-face support groups offer benefits such as shared experiences, shared values, and a shared common goal⁽¹⁷⁾, although challenges include geographical barriers, embarrassment, limited space and time constraints⁽¹⁸⁾. Computer-based online support may have similar benefits to its face-to-face counterpart, at the same time as allowing members access to information at a time and place of their choice and having the advantage of anonymity. However, online support may lack the personal rapport, immediacy and intensity of a face-to-face group meeting⁽¹⁸⁾. Studies have shown a positive influence of participation in traditional face-to-face support groups^(19–21) and computer-based support^(22,23) on QOL for individuals with chronic conditions such as breast cancer^(19,22,24) haemophilia⁽²⁵⁾, psoriasis⁽¹⁸⁾, irritable bowel syndrome^(26,27), Parkinson's disease⁽²¹⁾ and hepatitis B⁽²⁰⁾. In a recent study, individuals with CD who participated in an online education programme had higher QOL scores than those who received no intervention⁽²⁸⁾. However, little is known about the relationship between the use of different types social support networks (i.e. face-to-face, computer-based support or both) and QOL for individuals with CD. The present study aimed to evaluate the relationship between QOL scores of individuals with CD on a GFD and the different types of social support network use (i.e. face-to-face support, online support or both), as well as the frequency of use.

Materials and methods

A survey was administered in-person and online to a sample of adults with CD and following a GFD. A validated CD specific QOL questionnaire (CD-QOL) was used to determine QOL scores⁽²⁹⁾. Participation in social

support networks, as well as frequency and duration, was assessed, as well as the type of social support received from the various social support networks.

Setting and participants

A nonrandom and purposive sample was invited to participate, comprising adults with self-reported physician diagnosed CD who attended selected events between September 2012 and February 2013, or who responded to an online survey posted on various Internet sites between 6 and 21 August 2013. Participants in this cross-sectional study completed a questionnaire that measured coeliac-specific QOL, the use, frequency and duration of social support networks, as well as demographics. The present study was approved by Teachers College, Columbia University Institutional Review Board (IRB #12-371).

Recruitment

Participants were recruited either in-person or online. The purpose of the project was to make comparisons in QOL scores between individuals who used different types of social networks. Therefore, we recruited individuals from face-to-face, online and gluten-free events. Details of the locations of the events and support group meetings are provided in Table 1. Eligibility criteria included self-report of CD diagnosis and adherence to a GFD, age > 18 years and the ability to read and write English.

In-person recruitment

In-person recruitment included six CD support group meetings and five gluten-free conventions. *Gluten-free conventions*: The gluten-free conventions where people interact with food vendors, as well as attended lectures and cooking demonstrations, were attended by individuals who had an interest in the area of gluten, wheat or allergen-free foods. At all five conventions, the present research study was announced at the beginning of the convention and surveys were available at the sign in desk. There was a collection box for the surveys at a table by the exit door of the event. *Coeliac support groups*: The support groups host informational meetings for individuals who have been diagnosed with CD and their friends and families. At all six support group meetings, surveys were distributed at the beginning and collected at the end of the meeting.

Online recruitment

The online survey was announced through two online networks (i.e. Facebook and Twitter), as well as three

Table 1 Paper survey distribution and response rate

Distribution date	Distribution site	Distribution type	Number distributed	Number returned	Response rate (%)
8–9 September 2012	Dallas, TX	Expo	100	46	46.00
12 September 2012	Buffalo, NY	Expo	50	9	18.00
20 September 2012	Albany, NY	Support group	40	19	47.50
30 September 2012	Rye, NY	Expo	50	22	44.00
13–14 October 2012	Carmel, IN	Expo	50	39	78.00
16 October 2012	Livingston, NJ	Support group	30	26	86.67
21 October 2012	Boston, MA	Expo	100	47	47.00
1 November 2012	Akron, OH	Support group	15	15	100.00
12 November 2012	Chester, PA	Support group	15	9	60.00
19 December 2012	Toms River, NJ	Support group	15	9	60.00
13 February 2013	Orange, NJ	Support group	15	15	100.00
		Totals	480	256	53.33

coeliac specific social support networks (i.e. The Coeliac Diva, Gluten Dude, NYC Coeliac Disease Meetup Group). An announcement about the survey was posted from 1–10 August 2013 on the five sites. The announcement included a description of the research study, and a link to the online survey.

Measures

The survey comprised a total of 13 questions with multiple sub-questions. It was divided into three categories: demographics, QOL and social support network participation. Participants were asked about their coeliac diagnosis, length of time since diagnosis, length of time on the GFD and level of dietary adherence. The 20-item coeliac-specific QOL questionnaire (CD-QOL) was used⁽²⁹⁾. Social support measures included: the type of social support network used, the frequency and duration of social support used, and the reason for use of the various types of social support networks.

To identify the type of social support used, participants were asked to describe the type of social networks they used. Response options were face-to-face support group meetings (e.g. local support group meetings, meet-up groups, etc.); a variety of online social networks, such as Facebook, blog sites (e.g. Coeliac Diva, Gluten Dude), Pinterest, Twitter and LinkedIn; Video sites (YouTube, Vimeo); or 'Other'.

Reliability

The survey was given to subsamples of the population ($n = 28$) in both forms to determine whether both the online and paper format of the survey would provide reliable responses. The Cronbach reliability score for the paper to online was 0.71. The Mann–Whitney rank sum analysis was used with a resultant P value of 0.97,

indicating no statistically significant difference between the paper and online versions of the survey. The Cronbach score for online to online reliability was 0.82. The Mann–Whitney rank sum determined a P value of 0.97, indicating no statistically significant difference between tests.

Statistical analysis

Statistical analysis was performed using SAS, version 9.4 (SAS Institute Inc., Cary, NC, USA). $P < 0.05$ was considered statistically significant.

Demographic data were analysed using descriptive statistics, including means, frequency and standard deviation for gender, age, geographical location, level of education and length of time since diagnosis.

The QOL scores were analysed as per the validated CD-QOL survey protocol⁽²⁹⁾.

The scores were computed using the CD-QOL scoring system. The potential total QOL score is 100 points. The overall score ranks QOL from Poor (<40), Medium (40–59) and Good (>60). A pooled t -test was used to calculate the overall QOL score and between group comparisons. The generalised linear model procedure and bivariate regression was used to compare QOL mean scores and between group comparisons. Results were reported using the r^2 statistic.

The type and frequency of social support used were measured using descriptive statistics. The type and frequency of the social support network used were analysed using a multinomial logistic procedure and the chi-squared statistic. The type of social support network used in the various geographical regions was calculated using the frequency procedure and the chi-squared statistic. The frequency and duration of use for specific types of social support network use were analysed using the means procedure and analysis of variance.

Results

A total of 3734 individuals responded to the online survey, 2454 (65.7%) met the inclusion criteria and 1944 (79.6%) completed both the QOL and social support study portions of the survey and were included in the final analysis. Furthermore, a total of 480 in-person surveys were distributed at eleven different events, five food conventions and six CD support group meetings. Two hundred and fifty-six (53.3%) in-person surveys were returned, of which 197 (76.9%) met the inclusion criteria. One hundred and ninety-four of the 197 (98.4%) eligible participants completed both the QOL and social support study portion of the survey and were combined with the 1944 online survey responses for a total study sample of 2138 included in the analyses.

Description of sample characteristics

The level of education of the respondents was the only significant difference between the two methods of survey completion. Those responding via the in-person survey were better educated ($P = 0.01$). Of the total 2138 respondents, 87.3% were female.

Type of social support network used for social support

Participants were considered to use a social support network if they specifically reported that they sought 'social support' from traditional face-to-face or online groups targeted to coeliac patients. The majority of participants (58.4%) did not report using any type of social support. Among those who did, the largest portion used online only (17.9%). The number of respondents who used only face-to-face social support networks (10.8%) was similar to the number who used both online and face-to-face social networks (12.8%) (Table 2).

Type of social support used by demographic category

Significant differences were found between demographic characteristics and categories of social support network use for gender ($\chi^2 = 34.04$, d.f. = 3, $P < 0.0001$), age ($\chi^2 = 129.41$, d.f. = 12, $P < 0.0001$), length of time since

diagnosis ($\chi^2 = 46.30$, d.f. = 9, $P < 0.0001$) and level of education ($\chi^2 = 31.15$, d.f. = 12, $P = 0.0019$) (Table 3).

Men were more likely than women not to use any social support networks (70.0% for men versus 52.1% for women). When men did use a social support system, they used face-to-face, online or both social support networks equally (approximately 10% each). By contrast, women were more likely than men to use only online social support networks (21.2%) compared to face-to-face (10.8%) or both (16%).

The oldest age group (>65 years) was more likely to use only face-to-face support compared to the younger age groups. Younger age groups were more likely to use only online or both types. Participants with higher education were more likely to seek social support from social networks, and most likely to do so online compared to those with lower educational levels.

Quality of life

An overall mean QOL score of 68.9 was computed using the CD-QOL scoring of 100 points total, which is classified as good⁽²⁹⁾. The responses to the individual QOL questions describe an overall positive perception towards CD and the GFD. On the other hand, questions related to the social domain of QOL appeared to be most problematic for many participants, which is similar to the results reported in earlier QOL studies^(10,30,31). The QOL scores are reported by demographics category in Table 4. The overall mean QOL scores were in the 'good' range for both women [QOL score (SD)] [68.8 (16.49)] and for men [69.7 (17.35)], with no statistically significant difference between genders. By contrast, there were significant statistical differences for age ($P < 0.0001$), level of education ($P = 0.0009$) and length of time since diagnosis ($P < 0.0001$).

Quality of life scores by type of social support network

The data for QOL scores and the type of social support network are reported in Table 5. There was a significant relationship between the type of social support network used and QOL scores ($P < 0.0001$). Among those who used social support networks, those who participated in only face-to-face type of social support networks had the highest QOL scores [72.6 (16.19)] compared to those who participated only in online social support networks [66.7 (16.23)]. There was an increase, although not significantly, in QOL score for those individuals who used both types of networks for their social support.

The majority (54.3%) of respondents reported that they did not use social support networks for their social support. The QOL scores for this 'Neither' group were lower

Table 2 Type of social support network used for social support

	N	%
Neither	1249	58.40
Face-to-face	232	10.82
Online only	383	17.94
Both	274	12.79

Table 3 Type of social support networks used by demographics

	Total (n)	Neither	Face to Face	Online	Both	P
Gender						
Female	1857	967 (52.07)	200 (10.77)	393 (21.16)	297 (15.99)	<0.0001
Male	270	189 (70.00)	27 (10.00)	29 (10.74)	25 (9.26)	
Age (years)						
18–25	170	86 (50.59)	11 (6.47)	49 (28.82)	24 (14.11)	<0.0001
26–35	326	160 (49.08)	17 (5.21)	87 (26.69)	62 (19.02)	
36–55	897	469 (52.28)	77 (8.58)	205 (22.85)	146 (16.28)	
56–65	446	260 (58.29)	55 (12.33)	67 (15.02)	64 (14.35)	
>65	282	174 (61.70)	66 (23.40)	16 (5.67)	26 (9.22)	
Level of education						
High school	387	238 (61.50)	41 (10.59)	58 (14.99)	50 (12.92)	0.002
Technical vocational	176	110 (62.5)	17 (9.66)	26 (14.77)	23 (13.07)	
2 years of college	419	240 (57.28)	38 (9.07)	86 (20.52)	55 (13.13)	
4 years of college	641	311 (48.52)	73 (11.39)	150 (23.40)	107 (16.69)	
Advanced degree	494	247 (50.00)	59 (11.94)	102 (20.64)	86 (17.41)	
Length of time since diagnosis						
<6 months	119	63 (52.94)	8 (6.72)	30 (25.21)	18 (15.13)	<0.0001
6 months to 1 year	168	96 (57.14)	7 (4.17)	47 (27.98)	18 (10.71)	
1–3 years	560	288 (51.43)	50 (8.93)	143 (25.53)	79 (14.11)	
>3 years	1287	713 (55.40)	163 (12.66)	204 (15.85)	207 (16.08)	
Region/type of support						
Northeast	670	356 (53.13)	52 (7.76)	196 (29.25)	66 (9.85)	0.54
Midwest	530	270 (50.94)	39 (7.36)	177 (33.40)	44 (8.30)	
South	554	288 (51.98)	34 (6.14)	179 (32.31)	53 (9.57)	
West	384	190 (49.48)	23 (5.99)	124 (32.29)	47 (12.24)	

than the face-to-face group. However, the 'Neither' group scores were significantly higher [69.4 (17.08)] than for those who participated in online only [66.69 (16.23)] or both online and face-to-face networks [67.3 (16.19)].

When the QOL scores were controlled for the independent variables of age, length of time since diagnosis and level of education, the QOL scores were no longer statistically significantly different. The highest QOL score was seen in the group of respondents who reported no social support network use (66.69). Among the respondents who did use a social support network, the adjusted QOL scores were similar between face-to-face only (65.95) online only (65.46) and both (64.81) ($P = 0.51$).

Quality of life scores and frequency of social support network use

QOL scores were significantly associated with frequency of use ($P < 0.0001$) for any type of social support network. Interestingly, when analysed by the specific type of social support network used, there was a negative association between increased frequency of use of the online type of social support networks and QOL scores ($t = -7.35$, $P < 0.001$). Those who frequently used online social support the most had the lowest QOL scores. QOL scores in the face-to-face type of social support network

were not significantly associated with frequency of use ($t = -0.55$, $P = 0.5813$).

Quality of life scores and duration of social support network use

The duration of social support network use was significantly associated with QOL scores ($P < 0.0004$) for any type of social support network. The participants who used face-to-face type of social support had a positive significant association between QOL score and the length of time of use ($t = 3.48$, $P < 0.0005$). By contrast, there was a significant negative association between the online type of social support and increased duration of use ($t = -2.06$, $P < 0.0393$). For individuals using face-to-face support networks, a longer duration (i.e. number of months and years participating in face-to-face support networks) was associated with higher QOL scores. By contrast, a longer duration and a greater frequency of online use were both associated with lower QOL scores.

Discussion

The only treatment for CD is lifelong adherence to a GFD. As the guidelines from the British Society of Gastroenterology state, the aim of treatment is to promote

Table 4 Quality of life scores by demographics

Demographic characteristic	<i>n</i>	CD-QOL score	
		Mean (SD)	<i>P</i>
Gender			
Female	1857	68.8 (16.49)	0.25
Male	270	69.7 (17.35)	
Age (years)			
18–25	170	65.0 (17.13)	<0.0001
26–35	326	65.9 (16.88)	
36–55	897	67.3 (16.30)	
56–65	446	70.8 (15.99)	
>65	282	76.8 (15.01)	
Level of education			
High school	387	68.1 (17.83)	0.0009
Technical/vocational	176	67.0 (18.13)	
2 years of college	419	68.0 (16.86)	
4 years of college	641	68.5 (16.42)	
Advanced degree	494	71.7 (14.72)	
Length of time since diagnosis			
<6 months	119	62.7 (18.35)	<0.0001
6 months to 1 year	168	64.4 (14.72)	
1–3 years	560	65.2 (16.36)	
>3 years	1287	71.7 (16.19)	
Geographical region			
Northeast	670	70.39 (16.72)	<0.01
Midwest	530	67.24 (15.80)	
South	554	68.99 (16.34)	
West	384	68.54 (17.89)	

**P* is for *t*-test or analysis of variance. CD-QOL, coeliac disease specific quality of life questionnaire (Dorn *et al.* 2010).

Table 5 Quality of life scores by type of social support network used for social support

Type of social support use	<i>n</i>	QOL score	
		Mean (SD)	<i>P</i> < 0.0001
Neither	1337	69.4 (17.08)	<0.0001
Face-to-face only	235	72.6 (16.19)	
Online only	342	66.7 (16.23)	
Both	224	67.3 (16.19)	

QOL, quality of life.

healing, provide a nutritionally adequate intake, and mitigate symptoms and potential complications⁽³²⁾. However, this practice goal does not always match the reality of the day-to-day lives of individuals with CD. Eating comprises more than just filling ones nutritional needs. Meals are social events and often the thread that binds family and friends together. As noted in the study by Rose & Howard⁽¹⁴⁾, family meals and the social aspect of eating are changed once an individual is diagnosed with CD. The response of the group will affect the CD individual's

feelings of isolation, anxiety and overall QOL. Recommendations from several studies indicate the importance of support in adopting to the GFD, as well as coping with the disease^(13,15,28). Additionally, many studies on QOL in individuals with CD have shown the social domain, which includes family life and social interaction, to be most negatively affected^(10,11,31). Several studies have indicated the importance of connecting newly diagnosed patients with a coeliac support group^(14,15). Interestingly, Taylor *et al.*⁽¹⁵⁾ described the importance of support even beyond the traditional support group. They proposed that the connection with a trained healthcare provider may be vital to long-term dietary adherence, and increased awareness and understanding in social circles may decrease the feelings of isolation and socialisation anxiety⁽¹⁵⁾.

Several studies have shown a positive association of face-to-face support groups on QOL in individuals with various medical conditions^(19,20), albeit none on CD. There have also been multiple studies on the use and efficacy of face-to-face support group participation in the treatment and survivorship of various types of cancer patients^(17,19). These studies suggest that face-to-face support group participation had a positive effect on overall QOL scores, as well as continued health. A similar positive effect was found in the present study for participants in face-to-face support groups.

By contrast to the positive effect of face-to-face support, online social support network use was associated with lower QOL scores. These findings are similar to the results of the study by Kross *et al.*⁽³³⁾ conducted in the general population, where an increasing use of Facebook was associated with a significant decreasing sense of well-being, increasing loneliness and increased worry. The present study found that lower QOL scores were associated with a longer duration and greater frequency of the use of online social support networks. The increasing frequency of use associated with lower QOL scores and increased anxiety and depression may illustrate a problematic nuance of online networks. Online social networks may be able to provide constant technical connectivity but may not be able to provide the essence of support that users are seeking. Kross *et al.*⁽³³⁾ found that an increased number of direct face-to-face contacts mitigated the negative effect on QOL of the increased frequency of use of only Facebook.

Because the face-to-face social support network users had a higher QOL score among those using social support systems, future research needs to investigate the nuances of this particular support system that enhances QOL over participation in an online social support network. Identification of the effective attributes or differentiators of the face-to-face type of social support network may enable healthcare practitioners to develop

programmes that utilise these positive components within the growing technology and ease of online systems. There is great potential to design social support systems and educational programmes that incorporate the best of each type of social support network for this patient population in particular, as well as a broader population in general.

Strengths and limitations

The present study had several limitations. First, the study used a convenience sample of US adults with CD. Despite being a convenience sample, the sample did share characteristics similar to other CD populations described in the literature, albeit with a slightly higher female representation. The study sample was predominately female (87% compared to disease norms of 75%)⁽⁴⁾ and was diagnosed for longer than 3 years. A second limitation was the general definition used to define social support in the present study. Participants were simply asked whether or not they used the face-to-face or online social networks for social support. Future studies might want to consider using validated measures of social support such as the Social Support Questionnaire or the Medical Outcome Survey⁽³⁴⁾. Additional limitations included participants self-reported the diagnosis of CD and the inability to determine the response rate for the online surveys.

However, a major strength of the present study is that it is the first study to examine coeliac-specific QOL in adults who use social support networks. Second, the large sample size compared to other QOL studies and the diverse geographical representation of the respondents are strengths of the present study. Third, the present study used the recently validated disease specific QOL survey⁽²⁹⁾.

The purpose of this cross-sectional study was to examine the association between the use of different types of social support networks and QOL scores in individuals with CD. Participation in face-to-face social support networks is associated with greater QOL scores compared to online social support networks. The present study has generated a variety of questions that warrant further research. QOL scores are reported by raw scores determined by the different surveys used or occasionally categorically. However, the differences between the scores have not been assessed for clinical significance. An improvement in scores with an increasing length of time since diagnosis or an increase on a raw score both warrant further investigation to help guide clinical practice. However, from the results obtained, several practice points can be described. Although controlling for demographic variables decreased the statistical significance between participation in online and face-to-face networks, the overall positive trend of face-to-face participation is

clinically worth noting. These findings have potential implications for the management of individuals with CD. As Taylor *et al.*⁽¹⁵⁾ also noted, the use of face-to-face social support and connection with trained healthcare providers may be vital to overall QOL and GFD compliance. From this and other research^(15,19,20), it appears that practice recommendations for individuals with CD should include referrals to a coeliac support group and a coeliac specialist dietitian, as well as planned continued care and monitoring.

Conflict of interests, source of funding and authorship

The authors declare that they have no conflicts of interest.

No funding declared.

ARL was the primary researcher and the initiator of the research concept and design, and was also responsible for the primary analysis and interpretation of data, drafting of the manuscript, and final review and editing. RW, IC, HV and PHRG were responsible for study supervision and critical revision of manuscript for important intellectual content. All authors critically reviewed the manuscript and approved the final version submitted for publication.

References

1. Green PH & Cellier C (2007) Celiac Disease. *N Engl J Med* **25**, 1731–1743.
2. Cellier C, Flobert C, Cormier C *et al.*, (2000) Severe osteopenia in symptom-free adults with childhood diagnosis of coeliac disease. *Lancet* **355**, 806.
3. Green PHR & Jabri B (2006) Celiac disease. *Annu Rev Med* **57**, 14–15.
4. Murray J (1999) The widening spectrum of celiac disease. *Am J Clin Nutr* **69**, 354–365.
5. Hauser W, Janke K-H, Klump B *et al.*, (2012) Anxiety and depression in adult patients with celiac disease on a gluten free diet. *World J Gastroenterol* **16**, 2780–2787.
6. Holmes GK, Prior P, Lane MR *et al.*, (1989) Malignancy in coeliac disease -effect of a gluten free diet. *Gut* **30**, 333–338.
7. Hallert C, Granno C, Hulten S *et al.*, (2002) Living with celiac disease: controlled study of the burden of illness. *Scan J Gastroenterol* **37**, 39–42.
8. Ciacci C, D'Agate C, Franzese C *et al.*, (2003) Self-rated quality of life in celiac disease. *Digestive Disease Science* **48**, 2216–2220.
9. Cranney A, Zarkadas M, Graham ID *et al.*, (2007) The Canadian Celiac Health Survey. *Dig Dis Sci* **52**, 1087–1095.

10. Lee AR, Diamond B, Ng D *et al.*, (2012) Quality of life of individuals with celiac disease; Survey results from the United States. *J Hum Nutr Diet* **25**, 233–238.
11. Black JL & Orfila C (2011) Impact of celiac disease on dietary habits and quality of life. *J Hum Nutr Diet* **24**, 582–587.
12. Gray AM & Papanicolas IN (2010) Impact of symptoms on quality of life before and after diagnosis of celiac disease: results from a UK population survey. *BMC Health Serv Res* **10**, 105.
13. Sverker A, Hensing G & Hallert C (2005) Controlled by food- lived experiences of celiac disease. *J Hum Nutr Diet* **18**, 171–180.
14. Rose C & Howard R (2013) Living with coeliac disease: a grounded theory study. *J Hum Nutr Diet* **27**, 30–40.
15. Taylor E, Dickson-Swift V & Anderson K (2013) Coeliac disease: the path to diagnosis and the reality of living with the disease. *J Hum Nutr Diet* **26**, 340–348.
16. James SP (2005) National Institutes of Health consensus development conference statement on celiac disease, June 28–30, 2004. *Gastroenterology* **128**, S1–S9.
17. Bloom J (2008) Improving the health and well-being of cancer survivors: past as prologue. *Psycho-Oncology* **17**, 525–532.
18. Idriss SZ, Kvedar JC & Watson AJ (2009) The role of on line support communities. *Arch Dermatol* **145**, 46–51.
19. Kroenke, CH, Quesenberry, C & Kwan, ML *et al.*, (2013) Social networks, social support, and burden in relationships, and mortality after breast cancer diagnosis in Life After Breast Cancer Epidemiology (LACE) Study. *Breast Cancer Res Treat* **137**, 261–271.
20. Chao J, Song L, Zhang H *et al.*, (2013) Effects of comprehensive intervention on health-related quality of life in patients with chronic hepatitis B in China. *BMC Health Serv Res* **13**, 386.
21. Soh S, McGinley JL, Watts JJ *et al.*, (2012) Health-related quality of life of Australians with Parkinson disease: A comparison with international studies. *Physiother Can* **64**, 338–346.
22. Torkzahrani S, Rastegari L, Khodakarami N *et al.*, (2013) Quality of life and its related factors among Iranian cervical cancer survivors. *Iran Red Crescent Med J* **15**, 320–329.
23. Yoo, W, Namkoong, K, Choi, M *et al.*, (2014) Giving and receiving emotional support online: Communication competence as a moderator of psychosocial benefits for women with breast cancer. *Comput Human Behav* **30**, 13–22.
24. Gustafson DH, Hawkins R, Pingree S *et al.*, (2001) Effect of computer support on younger women with breast cancer. *J Gen Intern Med* **16**, 435–445.
25. Khair K, Holland M & Carrington S (2012) Social networking for adolescents with severe haemophilia. *Haemophilia* **18**, 290–296.
26. Amouretti M, LePen C, Gaudin A *et al.*, (2006) Impact of irritable bowel syndrome on health related quality of life. *Gastroenterol Clin Biol* **30**, 241–246.
27. Faresjo A, Foteini A, Lionis C *et al.*, (2006) Health-related quality of life of irritable bowel syndrome patients in different cultural settings. *Health Qual Life Outcomes* **4**, 21.
28. Jacobsson LR, Friedichsen M, Goransson A *et al.*, (2012) Impact of an active patient education program on gastrointestinal symptoms in women with celiac disease following a gluten-free diet: a randomized controlled trial. *Gastroenterol Nurs* **35**, 200–206.
29. Dorn SD, Hernandez L, Minaya MT *et al.*, (2010) The development and validation of a new celiac disease quality of life survey (CD-QOL). *Aliment Pharmacol Ther* **31**, 666–675.
30. Green PHR, Stravropoulos S, Pangagi S *et al.*, (2001) Characteristics of adult celiac disease in the USA: Results of a national survey. *Am J Gastroenterol* **96**, 126–131.
31. Barratt SM, Leeds JS & Sanders DS (2011) Quality of life in Coeliac Disease is determined by perceived degree of difficulty adhering to a gluten-free diet, not the level of dietary adherence ultimately achieved. *J Gastrointest Liver Dis* **20**, 241–245.
32. Ludvisson JF, Bai J, Biagi F *et al.*, (2014) Diagnosis and management of adult coeliac disease: guidelines from the British Society of Gastroenterology. *Gut* **63**, 1210–1228.
33. Kross E, Verduyn P, Demiralp E *et al.*, (2013) Facebook use predicts declines in subjective well-being in young adults. *Plos* **8**, 8.
34. Sarason IG, Levine HM, Basham RB *et al.*, (1983) Assessing social support: the social support questionnaire. *J Pers Soc Psychol* **44**, 127–139.