The perception of well-being; Do people with severe psychiatric conditions and their therapists put themselves in each other's shoes?

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Abstract

Subjective well-being (SWB) has been shown to be linked to better prognosis but research on it in people with severe psychiatric conditions (SCP) is sparse.

The main purpose of this study was to investigate SWB among individuals with SPC in comparison with the general population using a wide range of well-being measures. Also, we assessed the degree of agreement between professionals' and their corresponding patients' assessments of well-being. 237 people with SPC and 34 referring staff members participated in this study. People with SPC reported significantly lower levels of hedonic well-being but preserved eudaimonic well-being compared to the general population. However, a substantial proportion of participants with SPC had an average or above average SWB. We also found discrepancies between the well-being ratings of professionals and patients that were either negatively related or unrelated. These findings reinforce the importance of a more positive psychiatry, attuned to the patients' perception of well-being.

Keywords: Severe psychiatric illnesses; Subjective well-being; Life Satisfaction; Happiness; Empathy.

1. Introduction

Subjective well-being (SWB) has become a popular topic in the last two decades. Its importance has been reflected in policy-making processes (e.g. Azizan & Mahmud, 2018; Diener et al., 2009) and in the proliferation of research in this area. There has been an increase in the number of studies analysing SWB impact. It has been identified as a protective factor for morbidity (e.g. Howell et al., 2007) and mortality (e.g. Martín-María et al., 2017) and has been associated to improved functioning and resilience (Kansky & Diener, 2017). Moreover, its presence has been studied in a variety of conditions from depression (e.g. Helgeson et al., 2006) to HIV (e.g. Moskowitz et al., 2009) among many others.

Despite this renewed interest in the topic, SWB is not simple to define and tackle, and there has also been an upsurge in scientific research on how best to measure it (e.g. Cooke et al., 2016; Linton et al., 2016). It is a complex multi-dimensional construct that includes hedonic aspects such as the attainment of pleasure and happiness (Ryan & Deci, 2001) as well as eudaimonic aspects centred on the realisation of human potential (Waterman, 1993). According to Diener (1984), hedonic well-being comprises life satisfaction, the absence of negative and the presence of positive affect. While eudaimonic, as conceptualised by Ryff & Keyes (1995), it involves self-acceptance, life purpose, personal growth, personal relationships, autonomy and control of the environment. Happiness is more related to positive emotions while life satisfaction is related to the cognitive assessments and judgements people make about their lives when they think about it (Diener et al., 1999).

Given the traditional narrow focus on symptoms and deficits of communitarian psychiatry and clinical psychology (Seligman & Csikszentmihalyi, 2000; Slade et al., 2017), the research literature on SWB in people with severe psychiatric conditions (SPC) is sparse (Mankiewicz, 2015). This clinical population is characterised by severe and long-lasting distress and dysfunction as well as suffering social disadvantage and stigmatisation (Espinosa

& Valiente, 2017). Thus, the condition in itself has a great impact on a person's quality of life (Ritsner, 2011). To alleviate these tremendous costs and trying to increase hope, in recent years there have been calls for a more positive psychiatry with a greater emphasis on the well-being of the individual (Jeste et al., 2017; Mankiewicz, 2015). Besides, the presence of higher SWB in people with schizophrenia has been related to a better prognosis (Emsley et al., 2011), to improve therapeutic response (Schennach-Wolff et al., 2010; Slade, 2010) and even to increase adherence to medication (Fenton et al., 1997; Millas et al., 2006).

A good starting point to positivise mental health is to thoroughly assess the various dimensions of SWB in this population. In a large-scale study, Bergsma et al., (2011a) compared the level of happiness in people with and without mental disorders and found that happiness and life satisfaction were lower in those with mental disorders than in the general population. Unfortunately, even though they included a wide range of mental disorders, this study did not have enough people with conditions such as schizophrenia and were unable to report the level of happiness in some of the more serious psychiatric conditions (Bergsma et al., 2011a). There are a few studies that have investigated SWB in SPC. For instance, in a sample of people with first episode psychosis, Uzenoff et al. (2010) found that that the development of the disorder was associated with a decrease of SWB that was significantly predicted by perceived social support and lower levels of depression. Another very interesting study by Palmer et al., (2014) scrutinised happiness among people with unremitted schizophrenia and healthy controls. They found that although people with schizophrenia had lower levels of happiness, there was considerable heterogeneity in the perceived happiness and it could therefore be considered a viable treatment goal (Palmer et al., 2014). In fact, they indicated that happiness in their sample with schizophrenia was related to less stress, greater resilience, optimism and personal mastery (Palmer et al., 2014). In a sample of people with paranoid schizophrenia, Mankiewicz et al. (2013b) found that, compared to the general population, they

had elevated levels of anxiety and depression but similar levels of positive affect and only slightly lower levels of life satisfaction. Likewise, Palmer et al. (2014) argued that happiness and life satisfaction is possible in people with schizophrenia and that SWB should and could be targeted (Mankiewicz et al., 2013a, b).

It has been traditionally questioned whether people with SPC, especially those with schizophrenia, can adequately judge their subjective experience since they are often perceived as having a lack of insight (Lincoln et al., 2006; Mintz et al., 2003) and affective and cognitive distortions (Bergsma et al., 2011b). SWB is often measured using self-reporting (Cooke et al., 2016), which presumes that people are able to gauge their own experiences. However, there is some evidence that indicates that people with mental disorders are able to judge their life adequately and that measures of well-being had adequate concurrent, ecological and predictive validity (Bergsma et al., 2011b). A further question is whether the mental health professional is able to correctly discern the patient's well-being. A professional's empathy involves understanding the emotions of others (Decety & Jackson, 2004) and has been found to be essential in psychological therapy for psychoses (Shattock et al., 2018). Despite the importance of empathy in therapy outcomes, only a few studies have analysed discrepancies in the perspective of the practitioner and the patient in SPC (Rane et al., 2010). Day et al. (1998) studied the perception of neuroleptics by professionals and consumers, and they found that lack of understanding by professionals of what was causing the patient´s distress had an adverse effect on their therapeutic alliance. In a large sample of people with major depression, Demyttenaere et al. (2015a) found that professionals and patients differed significantly in what they considered important, while professionals focused on decreasing symptoms, patients focused on improving positive affect. What is most interesting is that they were able to demonstrate in a six-month follow-up study that discordance between professional and patient perception significantly predicted the clinical outcome (Demyttenaere et al., 2015b). In a recent

study, Wood et al. (2019) found significant discrepancies between the perspectives of staff and inpatients with psychosis regarding priorities for care, which could explain their dissatisfaction with the care received. Both patient and staff member perspectives should be considered to foster better therapeutic practices and outcomes (Shattock et al., 2018).

The primary aim of this study was to examine SWB in people with SPC in a cross-sectional study. For this purpose, and given the heterogeneity of well-being components, we selected different hedonic and eudaimonic measures to assess well-being in people with SPC and we compared it with general population means. We hypothesised that the general population would report higher subjective ratings of well-being than individuals with SPC would. However, we expected a good proportion of people with SPC with preserved SWB. Given the fundamental role of mutual understanding between staff members and patients, our second aim was to assess the degree of agreement between professionals' and their corresponding patients' assessments of well-being.

2. Methods

2.1. Participants

A total of 237 adult participants with SPC were assessed. They were recruited from NHS rehabilitation network from September 2018 to July 2019. SPC participants were included if they were aged 18–65 years, were receiving outpatient rehabilitation services and gave their consent to participate. Participants were excluded if they had limited cognitive resources or serious formal thinking disorder. Potential participants who had addiction problems in addition to the SPC were not excluded. 44 potential participants refused to take part in the study.

In addition, 34 referring staff members were recruited for this study. Staff members were included to participate if the patients they were counselling in the rehabilitation network had previously agreed to participate in the study. Mostly, the potential staff member

participants were psychologists that consented to participate, although social workers, occupational therapists and social educators also collaborated throughout the recruiting process.

The sample size of 237 users is above the number needed to calculate linear multiple regression with an average effect size (Cohen, 1992), ES = 0.5, a first alpha error of 0.05 and a power of 0.8 cores that would correspond to a minimum sample of 90 according to GPower (version 3.1) (Mayr et al., 2007).

2.2. Procedures

Participating rehabilitation centres and patients were debriefed about the characteristics of the study. Ethical approval for the study was obtained from the Faculty Deontological Commission and was conducted in compliance with the Declaration of Helsinki. After signing the informed consent form, patients were given an appointment by the staff member of their current rehabilitation centre where they filled out the evaluation SPC protocol that lasted about 45-60 minutes. After completion of the protocol by the patient, the referring staff member independently filled out a questionnaire about the patient's well-being that lasted about 15 minutes.

2.3. Measures

The SPC evaluation protocol included several self-report questionnaires with good psychometric properties to assess SWB as perceived by the patient participant. This protocol included:

2.3.1. Pemberton Happiness Index (PHI; Hervás & Vázquez, 2013).

This is an integrative measure of well-being. The scale includes 11 items related to different domains of well-being (i.e. general, hedonic, eudaimonic, and social) and 10 items related to well-being experienced the day before, all rated on a 0–10 Likert-type scale. The sum of these

items produced a combined well-being index where higher scores indicate higher well-being. In this study the Cronbach´s alpha was high (α =0.88).

2.3.2. Subjective Happiness Scale (SHS: Lyubomirsky & Lepper, 1999).

The SHS is a 4-item instrument of hedonic well-being rated on a 1–7 Likert-type scale that measures global subjective happiness by means of statements with which participants either self-rate them or compare themselves to others. High scores indicate greater happiness. In this study the reliability analysis was high (α =0.81).

2.3.3. Satisfaction with life scale (SWLS: Diener et al.,1985).

SWLS is a short scale composed of five simple items rated on a 1-7 Likert-type scale that measures satisfaction with life referring to an overall judgement of life experience in general. High scores indicate greater satisfaction with life. In this study the reliability analysis was also high (α =0.87).

2.3.4. The Scales of Psychological Well-Being (SPWB; Ryff, 1989).

This scale measures eudaimonic well-being and includes 29 items rated on a 1–5 Likert-type scale and 6 subscales (i.e. self-acceptance, purpose in life, personal growth, positive relationships, autonomy and environmental mastery). In our study, the Cronbach's alphas were high for self-acceptance, purpose in life (α =0.80, α =0.84, respectively), and moderate for personal growth, positive relationships, autonomy and environmental mastery (α =0.68, α =0.63, α =0.58, α =0.58, respectively).

The referring staff member evaluation protocol included sociodemographic and clinic data as well as a measure of well-being in the patient as perceived by the referring staff member. The staff-assessed well-being scale was:

2.3.5. The Scale of Quality of life (GENCAT: Verdugo et al., 2007).

The GENCAT scale is composed of eight subscales (i.e. emotional well-being, physical well-being, material well-being, interpersonal relationships, social inclusion, personal development,

self-determination and rights) and 69 items that measure the quality of life in adults over 18 years old rated on a 4-point Likert scale. The scale is evaluated by the referring therapist. For the purpose of the present study we have used the Emotional Well-Being scale. In this study the Cronbach´s alpha was (α =0.78).

2.3.6. *Concordance indexes of well-being (CI).*

CIs were calculated to determine the degree of congruence and discrepancy between the patient's perception and the corresponding well-being evaluation of their referring staff member. A CI was calculated for eight pairs of items. We selected, for each pair, one item rated by the patient from the SPWB and a similar item rated by the referring staff member in the GENCAT (see table 3). CI scores were calculated by transforming all selected items into z-scores for each pair, then the referring staff member z-score was subtracted to the patient´s z-score. Thus, a negative CI score indicated that the referring staff member perceived the patient's well-being better than the patient himself. While a positive score indicated that the patient's perception of well-being was better than the staff member's rating, and a CI score of zero indicated a consistent perception.

2.4. Data Analysis

All data were analysed using the Statistical Package for Social Sciences version 22 (IBM Corp, 2013). Social-demographic and clinical variables were analysed by central tendency measurements. To analyse the differences in SWB between general population and people with SPC, we used Student's *T*-tests one sample. Also, we analysed the association between the patient's well-being self-report and the professional's well-being ratings of patient´s by Pearson correlation analysis.

3. Results

Demographic and clinic characteristics of participants are shown in Table 1. The SPC sample seems representative of the population receiving services in the NMH rehabilitation

network. They were mostly single adult men with diagnoses of schizophrenia according to the DSM-5 (APA, 2013). Most of the sample had attained at least a secondary education and was unemployed, live with someone and have an associated disability and 16 years of evolution since first diagnosis of the mental illness.

Table 1.
Sociodemographic and clinical data of the SPC sample.

	SPC participants (N = 237)
Gender [n (%)]	
Male	*152 (64.1)*
Age [Mean (range)]	*41.7 (19-64)*
Civil Status [n (%)]	
Single	*209 (88.6)*
Married / Couple of fact	*11 (4.7)*
Separated / Divorced / Widower	*16 (6.8)*
Emigrant [n (%)]	
Yes.	*20 (8.4)*
Educational level [n (%)]	
Without Studies	*8 (3.4)*
Primary	*78 (32.9)*
Secondary	*119 (50.2)*
University	*32 (13.5)*
Employment Situation [n (%)]	
Unemployed	*200 (84.4)*
Type of coexistence [n (%)]	
Accompanied	*195 (82.3)*
Disability [n (%)]	
With disability	*214 (90.3)*
Principal diagnosis [n (%)]	
Psychotic Disorders	*149 (62.9)*
Personality Disorders	*36 (15.2)*
Bipolar Disorder	*29 (12.2)*
Others	*23 (9.7)*
Years of evolution since 1st diagnosis [Mean (DT)]	16.5 (9)
Substance use [n (%)]	
Yes	46 (19.4)

3.1. Differences between well-being in general population and in severe psychiatric conditions (SPC).

Student's *T*-tests analysis indicated that people with SPC have significantly less Global

Well-being (*p=.001*), positive relationship perception (*p=.001*), level of happiness (*p=.001*) and life satisfaction (*p=.001*) compared to the general population means. Emotional well-being as assessed by the referring therapist was also, significantly lower in SPC than in the general population (*p=.001*). However, Student's *T*-tests analysis indicated that there was no significant relationship between SWB and self-acceptance, autonomy, domain of the environment, purpose of life and personal growth. The results also show that it is possible to feel well-being despite having a SPC. For example, about 50% of individuals with SPC presented scores equal to or higher than the general population mean (i.e. on the self-acceptance, autonomy, purpose of life and personal growth dimensions of SPWB and on the GENCAT Emotional well-being). Even in those scales where they showed that SPC had significantly lower levels than the general population, almost a third of SPC individuals showed average or above average levels of positive relationships and life satisfaction (see Table 2).

Table 2.
Differences between well-being in general population and in severe psychiatric conditions

	GP	SPC		
	M (SD)	*M (SD)*	*t-test*	*% of SCP with WB equal to or greater than GP mean*
PHI - Global Well-being	6.92 (1.71)	6.22 (1.91)	-5.58**	38.39
SHS - Happiness	5.09 (1.03)	4.02 (1.25)	-13.12**	19.83
SWLS - Satisfaction with life	24.16 (5.73)	20.98 (7.49)	-6.65**	33.33
SPWB - Positive Relationships	4.20 (.70)	3.68 (.99)	-7.98**	35.44
SPWB - Self-acceptance	3.83 (.66)	3.86 (1.22)	.42	50.63
SPWB - Autonomy	3.55 (.83)	3.59 (.87)	.71	47.68
SPWB - Domain of the environment	3.81 (.78)	3.71 (.91)	-1.65	37.55

SPWB - Purpose of life	3.76 (.66)	3.86 (1.18)	1.40	58.22
SPWB - Personal growth	4.16 (.55)	4.20 (1.07)	.70	50.63
GENCAT -Emotional- WB	23.48 (4.98)	21.88 (4.36)	-5.63**	40.08

Note: GENCAT= Quality of Life Scale; GP = General Population; PHI = Pemberton Happiness Index; SHS = Subjective Happiness Scale; SPC= Severe Psychiatric Conditions. SPWB = Scales of Psychological Well-Being; SWLS = Satisfaction with life scale.
Source of general population data: GENCAT -Emotional- WB (*Verdugo, Arias, Gómez & Schalock, 2009;)* PHI (*Hervás & Vázquez, 2013*); SHS (*Extremera & Fernández-Berrocal, 2014*); SPWB (*Freire, Ferradás, Núñez & Valle, 2017) and* SWLS (*Vázquez, Duque & Hervás, 2013).*
* $p < .05$; ** $p<.001$.

3.2. Differences in SWB perception between patient and therapist and associated percentages.

We used Pearson's correlation analysis to determine the association between the patient's perception of well-being and the corresponding assessment by the referring staff member for the eight pairs of selected items (i.e. an SPWB item rated by the patient and an equivalent GENCAT items rated by the referring staff member). In particular, we found that six of the eight pairs of items had a significant negative relationship ($p<.01$). That means that when the patient rated his/her SWB positively or negatively, his/her therapist rated a similar item in the opposite direction (see table 3).

As can be seen in table 3, for all eight pairs of items, more than 50% of the times the referring staff member rating was higher than that of the patient (negative discrepancy) or lower than that of the patient (positive discrepancy).

Table 3.
Correlations between corresponding items of the SPWB and GENCAT, and percentages congruent and discrepant ratings

Item pairs	Content	*r*	-d (%)	c (%)	+d (%)
CII	SPWB Item 2: I often feel lonely because I have few close friends with whom to share my concerns. GENCAT Item 3: Complains of lack of stable friends	-.25**	24.1	51.5	24.5

CI2	SPWB Item 22: I haven't experienced many close and trusting relationships. GENCAT Item 4: Negatively values his or her relationships of friendship	-.12	27	46.8	26.2
CI3	SPWB Item 12: I feel that my friendships bring me many things. GENCAT Item 5: Your friends support you when you need them.	-.13*	24.5	46	29.5
CI4	SPWB Item 8: I don't have many people who want to listen to me when I need to talk. GENCAT Item 7: Your friends are limited to those who attend the centre.	-.13*	28.7	41.8	29.5
CI5	SPWB Item 17: I like most aspects of my personality. GENCAT Item 6: He's satisfied with him/herself.	-.29**	32.1	35	32.9
CI6	SPWB Item 3: I am not afraid to express my opinions, even when they are opposed to the opinions of most people. GENCAT Item 4: Defends your ideas and opinions.	-.03	27.8	45.1	27
CI7	SPWB Item 20: I have a clear direction and purpose in my life. GENCAT Item 1: Has personal goals, objectives, and interests.	-.19**	30.8	38.4	30.8
CI8	SPWB Item 11: I am an active person in carrying out the projects I proposed for myself. GENCAT Item 4: Organise his/her life.	-.26**	29.5	46	24.5

Note: CI= concordance index; GENCAT= Quality of Life Scale filled out by the professional; -d = negative discrepancy (the professional rating is higher than that of the patient); c = congruent (similar rating by referring staff member and the patient); +d = positive discrepancy (the referring staff member rating is lower than that of the patient). SPWB = Scales of Psychological Well-Being filled out by patient.
* $p < .05$; ** $p<.001$.

4. Discussion

The main purpose of this study was to investigate SWB among individuals with SPC using a wide range of well-being measures. Individuals with SPC reported lower well-being than general population in global measures of hedonic well-being (PHI and SHS) and life satisfaction. These findings are in line with other studies that have found lower levels of happiness and life satisfaction among people with mental disorders in comparison with the general population (Bergsma et al., 2011a; Fervaha et al., 2016; Palmer et al., 2014). They are complementary to Bergsma's findings since they did not include some of the more serious psychiatric illnesses that we did, and to Palmer's findings since their sample was comprised exclusively of people with unremitted schizophrenia while our sample was more heterogeneous. However, our results are inconsistent with previous studies that indicated that young people with a first psychotic episode were as happy as healthy controls (Agid et al., 2012). It could be that this decline in happiness and life satisfaction has to do with the degree of chronification given that our sample had a high degree of chronicity and disability.

Nonetheless, even though the mean levels of happiness and life satisfaction are lower for SPC, there seems to be a marked overlap in the scores with the general population. In fact, many of the participants with SPC endorse high levels of SWB, with a high proportion at or above the general population average in all the different SWB measures. This data is consistent with other studies that have found that there is a high proportion preserved well-being among young adults with schizophrenia (Fervaha et al., 2016), individuals with paranoid schizophrenia (Mankiewicz et al., 2011) or a wide range of mental disorders (Bergsma et al., 2011a). This indicates that well-being is

possible despite SPC and should therefore be a therapeutic target as it is associated with a better prognosis (Emsley et al., 2011).

Interestingly, the current study did not find significant differences in five of the six eudaimonic subscales as measured by the SPWB. Likewise, Valiente et al. (2014) found preserved levels of self-acceptance, autonomy, domain of the environment, purpose of life and personal growth in inpatients with paranoid schizophrenia in comparison with a healthy control group. It should be noted that only in the positive relationship SPWB subscale, our sample reported lower levels compared to the general population. Given the tremendous importance of successful social relationships for both mental and physical health (Mushtaq et al., 2014), these results indicate that interventions for this clinical population should be targeted particularly at social welfare.

However, and contrary to what happens with happiness, some studies have found that the development of psychosis is associated with a decrease in eudaimonic well-being (Uzenoff et al., 2010). It could be that the impact on the SWB varies depending on the stage of the disease course. The eudaimonic well-being is associated with the realisation of one's potential or of the true nature, the functioning at an optimal level (Lent, 2004) and the irruption of the psychosis represented by the individual in an abrupt rupture of his/her expectations. Conversely, people with a more chronic clinical picture have had time to adapt and often are receiving rehabilitation services where they usually focus on the development of independent living skills and functioning (González & Rodríguez, 2010).

It is noticeable that according to our results in this SPC population there is a persevered eudaimonic and a diminished hedonic well-being. The decreased hedonic

response may be explained in part by a diminished affective response associated with depression and schizophrenia (Barch et al., 2015). Moreover, many of the people in our sample had more than one prescribed antipsychotic medication, which could impact emotions and motivation (Thompson et al., 2019). Nevertheless, this discrepancy warrants further consideration in future research.

Our second aim was to assess the degree of agreement between professionals' and their corresponding patients' assessments of well-being. As far as we know, this is the first study that compares the well-being as rated by professionals and their patients affected by SPC. It is noteworthy that the professionals' and patients' ratings were negatively related or unrelated, indicating a lack of mutual understanding in relation to SWB. This finding is remarkable given the great importance and prognostic value of an empathic understanding among professionals and their patients (Day et al., 1998; Demyttenaere et al., 2015a). It is possible that professionals and people with SPC are focusing their attention on different aspects of well-being. While the professional might be fixated on psychosocial functioning and symptoms, their patients might be more concerned with his/her emotions. Likewise, Demyttenaere et al., (2015a) found that professionals differ significantly from patients with regards to what they consider important for healing from depression. While they focused primarily on the relief of the clinical symptoms, patients focused primarily on the recovery of positive affect. Efforts should be done to reduce this gap and future research should investigate this discrepancy further.

There are some of limitations in the current study. It did not explore objective indicators of well-being. Thus, it appears essential that future studies explore both subjective and objective well-being as well as psychological distress amongst

individuals experiencing SPC. Moreover, our current study did not include in the protocol a scale to evaluate the alliance between the referring staff member and the patient. It is likely that the degree of well-being agreement could be conditioned by the strength of their working alliance. Furthermore, it would be interesting to be able to do a prospective cohort study to see how the level of well-being agreement evolves over time. Finally, it is important to note the moderate reliability of some measures of eudaimonic well-being dimensions. It could be due to the considerable heterogeneity of these instruments compared with the hedonic instruments (Cooke et al., 2016).

Given the prognostic value of well-being (Emsley et al., 2011) and the lack of research in SPC (Mankiewicz et al., 2015), studies aimed to understand well-being in this population are essential. This study draws attention to the need of increasing the awareness of professionals in their patients' perception of well-being and monitoring it on a regular basis. Moreover, the lower levels of SWB calls for specific intervention to target positive outcomes such as positive psychology interventions that have shown not only a significant improvement in well-being, but also a secondary improvement in symptoms (Bolier et al., 2013). Although supporting evidence is scarce, positive psychology for psychosis appears to be a promising intervention enhancing recovery (Meyer et al., 2012; Schrank et al., 2016; Valiente et al., 2019). Our findings are in line with the growing awareness of the importance of well-being in SPC recovery and rehabilitation and indicate that mental health and rehabilitation services should evaluate different aspects of SWB so that mental health professionals and health policies become more sensitive to these positive care needs. These developments will improve the comprehensiveness of the interventions provided to people with SPC.

Acknowledgments and funding

We are grateful to the participants and referring staff members that were willing to complete the measures. The authors thank James L. O'Grady for proofreading the article. We are very grateful to the NHS rehabilitation Network that supported and welcomed our research. This research was supported by grants from the Ministry of Science and Innovation [PSI2016-74987-P].

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