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Positive Psychological Change in Head and Neck Cancer populations

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ABSTRACT

Head and neck cancer (HNC) carry a high level of morbidity and mortality, but the impact of HNC on survivors differs widely among individuals, and a significant number of them suffer from negative psychological effects of the disease. However, some people report a significant positive effect of experiencing HNC and its treatment.

This review looks at demographic, clinical and psychological factors associated with positive psychological change (PPC) in HNC populations.

Eight quantitative manuscripts were identified as reporting on PPC in HNC. These studies were split between recruiting participants via cancer clinics and postal surveys, and the majority use a cross-sectional study design.

Demographic factors across the papers showed similar patterns of relationships across PPC; that higher education/qualification and cohabitation/marriage are associated with increased PPC. Limited research reported longitudinal patterns of change and showed that for people with lower stage tumours and those who only had a surgical intervention greater PPC developed over time. Multivariable modeling adjusting for psychosocial variables found that PPC had a quadratic relationship with time since diagnosis, increasing initially and leveling off after 18 months.

Further research would aid the identification of bio-psychosocial factors that influence the development of PPC and inform the development of rehabilitation interventions while enabling consideration of the natural development of the phenomenon.

Introduction

There is evidence from the literature that some people report benefit from illness[1-6]. In some cases, these benefits go some way to mitigating the negative consequences of illness, but there are also instances where people report an overall benefit of being ill. Positivity in adversity has been cited in the context of other stressful life events such as combat and imprisonment, divorce, care giving and bereavement[7]. Stress-related growth in adversity is reported to be 'remarkably common'[7].

There is a growing body of literature supporting the suggestion that a stressful or traumatic event may be a catalyst for positive psychological change[8,9]. In 1991 Yalom and Lieberman[10] used the term 'positive psychological changes' to refer to positive changes in the perceptions of oneself, social relationships with family and friends and life priorities and appreciation of life. These positive changes, which have also been referred to as 'perceived benefits', 'benefit finding', 'thriving', 'stress-related growth', 'adversarial growth', 'post-

traumatic growth', or 'existential growth', may concern changes in the perceptions of oneself, social relationships with family and friends and life priorities and appreciation of life. The term 'Post-traumatic growth' is widely used due to its ability to describe the need for individuals to have experienced trauma before they experience positive change over time. However, premininent researchers in this field, Tedeschi and Calhoun, have suggested this these terms are roughly synomous[11]. In this paper, positive psychological change (PPC) will be used unless reporting data directly from a journal article where they use another term such as PTG. The choice of PPC over PTG was made due to the nature of the trauma experienced by the people with and following cancer. In presenting work on PPC to people who have received a diagnosis of head and neck cancer (HNC) the author has found that the word 'growth' has significant negative meaning, as it is a word associated with a cancerous tumour. In working with this group of people, Harding et al[12] suggest that the phrase positive psychological change was better received and facilitated communication.

Within the field of cancer, breast cancer (BC) has received the greatest amount of investigation into PPC[13-18]. There is evidence indicating that a substantial number of BC survivors experience such positive changes, especially in the long term[15-17,19,20]. Cancer survivors from tumours in a range of locations frequently report having altered priorities including more concern for others, a greater sense of purpose and a greater appreciation of themselves and their lives life[4,21-24]. A challenge for HNC clinicians is to understand what factors are associated with the developed of PPC. Only eight quantitative articles have been published within the field of HNC and PPC[25-32]. Tables 1 and 2 provide an outline of the study designs, participants, and variable.

This over view of the current literature will describe

Table 1: Study Descriptors.

Study	Author(s)	Aim of the study	Study Design	Study measures	Demographic Factors	Medical Factors	Time of measurement
1	Harrington, S., McGurk, M. & Llewellyn, C.D. (2008)	1) to determine the extent to which patient treated for HNC experience positive consequences of their illness, 2) to identify factors associated with benefit finding among this patient group	Cross-sectional postal survey	Benefit finding scale (BFS), Hospital Anxiety and Distress Scale (HADS), Life Orientation Test - Revised (LOT-R), Brief COPE	Age, Gender, Ethnicity, Education, Employment, Marital status	Type of treatment, time since last treatment, diagnosis of further illness since treatment, site, type of cancer and stage of cancer	0-6mths = 1, 6-12mths = 3, 13-24mths = 7, 25-47mths = 20, 48-72mths = 19, 73-121mths = 26
2	Llewellyn, C.D., Horney, D.J., McGurk, M., Weinman, J., Herold, J., Altman, K. & Smith, H.E. (2011)	1) to determine the extent to which patient treated for HNC experience positive consequences of their illness, 2) to establish the relationship between BF, other patient-reported outcomes and predictive factors such as coping strategy and level of optimism	Repeated measures prospective study using self-completion questionnaires	Benefit finding scale (BFS), Hospital Anxiety and Distress Scale (HADS), Life Orientation Test (LOT-R), Brief COPE, Medical Outcomes Short Form 12 (SF-12), Two-item measure derived from The European Organization for Research and Treatment (EORTC) of Cancer Quality of Life Questionnaire (QLQ-C30)	Age, Gender, Ethnicity, Education, Employment, Marital status	Type of treatment, site and stage of cancer	T1 = Between diagnosis and start of treatment, T2 = 6 months after completion of treatment
3	Ho, S.M.Y., Rajandram, R.K, Chan, N., Samman, N., McGrath, C. & Zwahlen, R.A. (2011)	Investigate if PTG occurs in oral cancer patients and if hope and optimism shows significant positive correlation with PTG	Cross-sectional postal survey	Chinese Posttraumatic Growth Inventory (PTGI), Hope scale (HS), Life Orientation Test - Revised (LOT-R)	Age, Gender, Religion, Education level, income	Time since diagnosis, stage of disease, and treatment type	Mean time was 3.6yrs (SD 0.34)
4	Lebel, S. Costonguay, M., Mackness, G., Irish, J., Bezjak, A. & Devins, GM. (2013)	Investigate if the relationship between stigma and subjective well-being will be moderated by benefit finding (the negative impact of stigma on distress and subjective well-being will be lower when people report high levels of benefit finding	Cross-sectional postal survey	Affect Balance Scale (ABS), Center for Epidemiological Studies Depression Scale (CES-D), Explanatory Model Interview Catalogue (EMIC), Illness Intrusiveness Ratings Scale (IIRS), Posttraumatic Growth Inventory (PTGI), Disfigurement Scale, Marlowe-Crown Social Desirability Scale	Age, Gender, Martial status, number of children, number of other people in the home, employment status, education, annual household income, country of birth, religion, stressful life events.	Years since diagnosis, Cancer stage, treatment type	Mean time was 1.37 (SD 0.84) years since diagnosis

5	Leong Abdullah, M.F., Nik Jaafar, N.R., Zakaria. H., Rajandram, R.K., Mahadevan ,R., Mohamad Yunus, M.R. & Shah, S.A. (2015)	Investigate the correlations between PTG with depression and anxiety.	Cross-sectional	Posttraumatic Growth Inventory – Short Form (PTGI-SF), Hospital Anxiety and Depression Scale (HADS)	Age, Gender, Race, Monthly income, educational level, marital status	Diagnosis, duration of diagnosis, treatment regime, Cancer stage	T1 = Within 1 year of diagnosis, T2 = 6 months following T1
6	Holtmaat, K., van der Spek, N., Cuijper, P., Leemans, C.R. & Verdonck-de Leeuw, I.M. (2016)	Investigate the occurrence of PTG among HNC survivors with psychological distress and to examine the associations of PTG with sociodemographic and clinical factors, nicotine and alcohol use disorders, anxiety and depression disorders and health-related quality of life	Cross-sectional	Posttraumatic Growth Inventory (PTGI), Hospital Anxiety and Depression Scale (HADS), European Organization for Research and Treatment of Cancer Quality of Life Questionnaire – C30 (EORTC QLQ-C30) World Mental Health CIDI	Age, Gender, marital status, years of education, employment status	Tumour location, Cancer stage, Treatment regime, Months since treatment, CIDI diagnosis	Mean time was 22.4 (SD 25.8) months since diagnosis
7	Harding, S. & Moss, T.P. (2017)	Investigate the relationship between biomedical variable, health-related quality of life, social factors and subjective reports of PPC	Cross-sectional postal survey	Silver Lining Questionnaire (SLQ), University of Washington Head and Neck Caner Quality of Life (UoW), Medical Outcomes Short Form 12 (SF-12)	Age at diagnosis, Age at time of completing questionnaire, Gender, Ethnicity, Index of Multiple Deprivation, Occupation, Family Status	Cancer stage, Treatment regime, Months since treatment,	Mean time was 6.52 (SD 2.8) months since diagnosis
8	Harding, S. (2017)	Investigate the pattern or trajectory of development of PPC over a 5 year time period. Investigate how biological, social and psychological variable are associated with PPC	5 year cross-sequential	Silver Lining Questionnaire (SLQ), University of Washington Head and Neck Caner Quality of Life (UoW), Medical Outcomes Short Form 12 (SF-12)	Age at diagnosis, Age at time of completing questionnaire, Gender, Ethnicity, Index of Multiple Deprivation, Occupation, Family Status	Cancer stage, Treatment regime, Months since treatment,	Seven time categories are used: 1) 3-6 months 2) 7-12 months 3) 13-18 months 4) 19-24 months 5) 25-36 months 6) 37-60 months 7) ≥61 months

Table 2: Participants and Variables.

Study	Author(s)	Participants (Gender, Age)	Time of measurement	Non-respondents / Dropouts	Exclusion Criteria	Cancer Site	Cancer Staging	Cancer Treatments	Time since completion of treatment
1	Harrington, S., McGurk, M. & Llewellyn, C.D. (2008)	N = 76 (55% response rate; 37 Male, 39 Female; Mean Age 66.9, SD 12.6, Range 32-97; 71 White)	0-6mths = 1, 6-12mths = 3, 13-24mths = 7, 25-47mths = 20, 48-72mths = 19, 73-121mths = 26	Significant difference between gender in responders and non-responders (more females responding)	Under 18 years of age. Having palliative treatment. Recurrent diagnosis, metastatic disease in other parts of the body (excluding neck nodes), a diagnosis of lymphoma, mental to cognitive impairments or insufficient understanding of English.	Not stated	Stage 1-2 - N = 53, Stage 3-4 - N = 23	Surgery only - N = 35, Radiotherapy only - N = 10, Surgery and Radiotherapy - N = 30, Surgery, radiotherapy and chemotherapy - N = 1	0-6 months = 1, 6-12 months = 3, 13-24 months = 7, 25-47 months = 20, 48-72 months = 19, 73-121 months = 26
2	Llewellyn, C.D., Horney, D.J., McGurk, M., Weinman, J., Herold, J., Altman, K. & Smith, H.E. (2011)	T1. N = 103 (73 Males, 30 Females; Mean Age 63, SD 13.9, Range 23-91; 93 White). T2. N = 68 (Gender, Age, Ethnicity data provided)	T1 = Between diagnosis and start of treatment, T2 = 6 months after completion of treatment	There were no significant differences between patients included and not included with respect to gender, stage of cancer. 35 people did not complete the second time point. No information is given about they compared at T1	Under 18 years of age. Having palliative treatment. Recurrent diagnosis, metastatic disease in other parts of the body (excluding neck nodes), a diagnosis of lymphoma, mental to cognitive impairments or insufficient understanding of English.	Oral Cavity - N = 68, Pharynx - N = 8, Larynx - N = 19, Other - N = 8	Stage 1 - N = 34, Stage 2 - N = 25, Stage 3 - N = 23, Stage 4 - N = 17, Missing data - N = 4	Surgery only - N = 36, Radiotherapy only - N = 25, Chemotherapy only - N = 3, Surgery and Radiotherapy - N = 17, Radiotherapy and chemotherapy - N = 13, Surgery, radiotherapy and chemotherapy - N = 9	Six months at T2

3	Ho, S.M.Y., Rajandram, R.K, Chan, N., Samman, N., McGrath, C. & Zwahlen, R.A. (2011)	N = 50 (21 Male, 29 Female), Mean Age 60, (SD 13.06)	Mean time was 3.6yrs (SD 0.34)	No information is reported	Non-native Cantonese speakers, less than 6mths post treatment completion, recurrence	Oral Cavity, Oropharynx, gingival, floor of mouth, tongue, salivary glands, buccal mucosa, palate. Numbers at each site not stated.	Stage 1-2 - N = 41, Stage 3-4 - N = 5, Missing information - N = 4	Surgery only - N = 34, Surgery and Radiotherapy - N = 16	Mean time was 3.6yrs (SD 0.34)
4	Lebel, S. Costonguay, M., Mackness, G., Irish, J., Bezjak, A. & Devins, GM. (2013)	N = 99 (48 Males, 51 Female) Mean Age 61.82 (SD .63)	Mean time was 1.37yrs (SD 0.84)	No data presented between responders and non-responders	Diagnosis of secondary ore recurrent HNC, under 18 years of age, illiterate, still to undergo surgery, more than 3 years post treatment	Not stated	60% identified as local disease, 40% advanced disease	Surgery only - N = 52, Surgery plus other - N = 47, Chemo - N = 7, Radiotherapy - N = 45, Other - N = 4	Mean time was 1.37yrs (SD 0.84)
5	Leong Abdullah, M.F., Nik Jaafar, N.R., Zakaria. H., Rajandram, R.K., Mahadevan ,R., Mohamad Yunus, M.R. & Shah, S.A. (2015)	N = 50 (33 Males, 17 Female), Mean Age 49.76 (SD 11.56)	T1 = Within 1 year of diagnosis, T2 = 6 months following T1	No data presented between responders and non-responders	Greater than 1 year post diagnosis, distant metastases, in a relationship for less than 6 months	Not stated	Stage 1 - N = 11, Stage 2 - N = 14, Stage 3 - N = 12, Stage 4 - N = 13	No treatment – N = 20, Surgery only - N = 8, Radiotherapy only - N = 4, Chemotherapy only - N = 3, Surgery and Radiotherapy - N = 2, Surgery and chemotherapy – N = 1, Radiotherapy and chemotherapy - N = 8, Surgery, radiotherapy and chemotherapy - N = 4	T1 = Within 1 year of diagnosis, T2 = 6 months following T1
6	Holtmaat, K., van der Spek, N., Cuijper, P., Leemans, C.R. & Verdonck-de Leeuw, I.M. (2016)	N = 74 (43 Males, 31 Females), Mean Age 61.2 (SD 8.5)	Mean time was 22.4 (SD 25.8) months since diagnosis	No difference in gender or HADS score, but those that declined were older (P<0.05)	Less than 1 month post treatment, <7 on the depression and/or anxiety subscale of HADS, cognitive dysfunction, high suicide risk, psychotic and/or manic signs, too little knowledge of Dutch to complete questionnaires	Lip, oral cavity, oropharynx, hypopharynx, larynx	Stage 1 or 2 - N = 33, Stage 3 or 4 - N = 37, Unknown – N= 4	Surgery – N = 12, Radiotherapy- N = 27, Chemotherapy – N = 10, Combination surgery and other – N = 25	Mean time was 22.4 (SD 25.8) months since diagnosis
7	Harding, S. & Moss, T.P. (2017)	N = 52 (36 Male, 16 Female), Mean Age 65.63 (SD 10.31)	Mean time was 6.52 (SD 2.8) months since diagnosis	No difference between responders and non-responders on medical or demographic factors	<18 years old, too little knowledge of English to complete questionnaires, tumour not histologically diagnosed as squamous cell	Mouth, lip, oral cavity, salivary gland, pharynx, nasal cavity, sinuses	Stage 1 - N = 10, Stage 2 - N = 1, Stage 3 - N = 13, Stage 4 - N = 26	Surgery – N = 16, Surgery and radiotherapy – N = 17, Radiotherapy ± chemotherapy – N = 18	Mean time was 6.52 (SD 2.8) months since diagnosis
8	Harding, S. (2017)	Seven time points: 1) 3-6 months – 65.59 (SD 11.54) 2) 7-12 months – 63.43 (SD 8.93) 3) 13-18 months – 59.41 (SD 9.05) 4) 19-24 months – 59.55 (SD 12.91) 5) 25-36 months – 64.95 (SD 15.34) 6) 37-60 months – 58.87 (SD 10.86) 7) ≥61 months – 57.64 (SD 10.69)	Seven time categories are used: 1) 3-6 months – N = 40, 2) 7-12 months – N = 37, 3) 13-18 months – N = 22, 4) 19-24 months – N = 11, 5) 25-36 months – N = 20, 6) 37-60 months – N = 23, 7) ≥61 months – N = 25	No difference between responders and non-responders on medical or demographic factors	<18 years old, too little knowledge of English to complete questionnaires, tumour not histologically diagnosed as squamous cell, recurrence over the time of data collection, new tumour diagnosed in any location	Mouth, lip, oral cavity, salivary gland, pharynx, nasal cavity, sinuses	Data for 7 time categories is presented in full paper. Data for 3-6 months was: Stage 1 - N = 9, Stage 2 - N = 5, Stage 3 - N = 5, Stage 4 - N = 18	Data for 7 time categories is presented in full paper. Data for 3-6 months was: Surgery – N = 16, Surgery and radiotherapy – N = 14, Radiotherapy ± chemotherapy – N = 8	Seven time categories are used: 1) 3-6 months 2) 7-12 months 3) 13-18 months 4) 19-24 months 5) 25-36 months 6) 37-60 months 7) ≥61 months

which variables have been found to be associated with PPC in people following HNC. The current research literature does not provide many clear associations due to the limited number of studies. Most studies are also short duration which makes it more difficult to evaluate changes over time about identified variables.

What variables are associated with PPC in people following treatment for HNC

Some variables may mediate the relationship between trauma and PPC. Within studies, these variables can be categorized as demographic, clinical and psychological.

Demographic factors

Using a cross-sectional design with mixed cancer sites, Park *et al*[33] found, in a mixed cancer site study, that women consistently reported higher levels of PPC than men. However, this study was of a largely young female cohort, over a comparatively short period (1 year) which makes it difficult to extrapolate to HNC survivors or other cancer sites, especially over an extended time frame.

In contrast to this, studies across cancer sites have found no relationship between gender and PPC in colorectal cancer[34], hepatobiliary (having to do with liver, bile ducts, and bile) cancer[35] or HNC[25,27,28]. Holtmaat *et al*[29] found females developed more PPC than their male cohort in an HNC population, although no reason for this is offered.

To date, no published studies have found an impact of age on PPC in HNC, though it has been found that younger participants with BC reported higher levels of PPC[36,37]. The greater number of studies undertaken with BC patients, and the larger participant numbers in those studies (due to the greater occurrence of BC in the general population), has identified age as a factor in the trajectory of change in, and final level, of PPC in BC[15,16].

No clear relationship has been found between to ethnicity and PPC. Bellizzi *et al*[13] found that African-Americans treated for BC showed higher levels of PPC than Caucasians, whereas Kent *et al*[18] found Caucasians with BC had higher PPC than African-Americans but not higher than Hispanics[13,18]. Studies of PPC across other traumas also found a mixed pattern. Milam[38], for example, investigated AIDS/HIV and found that African-American and Hispanic participants reported higher levels of PPC than Caucasians respondents.

Educational attainment also lacks a clear relationship with PCC. A narrative systematic review by Koutrouli *et al*[39] found that most studies reported that people with BC and lower education levels experienced higher levels of PPC. One study of HNC found higher educational level was associated with greater PPC[32] and another found no association with education[28].

Three studies following treatment for HNC reported a beneficial effect of marriage or stable cohabiting over single status in the reporting of PPC[25,26,2]. Although when assessed longitudinally Harding[25] found no impact from marital status. In a study that examined the perspectives of BC patients and their partners, Manne *et al*[37] measured marital quality and, despite concluding that partners influenced the course of PTG over time, they were not responsible for its prediction. This suggests that a stable social support system may have advantages over and above a high-quality one-to-one interaction.

Only one HNC study assessed the impact of socio-economic status and found that those participants with high or low socio-economic status reported greater levels of PPC than those in the middle of the scale[25].

Clinical factors

Eight HNC studies have investigated clinical factors of PPC[25-32] using quantitative PPC measures. Harrington, McGurk, and Llewellyn[27] did not find any relationship between PPC and treatment, time since treatment, stage of cancer or diagnosis of further illness in people treated for HNC. Leong *et al*[31] did not find an association with stage of the tumour with development of PPC either. This pattern was partially reinforced by the findings of, Harding[25], Harding and Moss[26], Holtmaat *et al*[29] and Llewellyn *et al*[32].

Ho *et al*[28] found that following HNC people with more advanced cancer (stages III and IV) reported a lower levels of PPC, but different treatment modalities did not significantly influence PPC. The pattern of tumour stage was supported by the work of Harding[25] and Harding and Moss[26]. In relation to treatment modalities, Harding[25] and Harding and Moss[2] found that participants who had surgery alone reported more positive change than both those who had surgery with radiotherapy and those who were not treated surgically, but who had received radio-therapy with or without chemotherapy.

When compared to studies undertaken in BC[15,164], the eight HNC studies have small sample sizes and lack clarity over the potential impact of, and mediating factors of, co-morbidities on PPC trajectories[25-32].

Psychological factors

Harrington, McGurk, and Llewellyn[27] recruited people with HNC and found that dispositional optimism and positive reframing could account for 23% of the variance in PPC and additionally that higher levels of religious coping were correlated with greater PPC. They did not find any relationship between PPC and anxiety, or depression. Llewellyn *et al.*[32] supported Harrington *et al's*[27] findings related to dispositional optimism and positive reframing, and also found that increased use of emotional support and a decrease in self-blame positively affect PPC. This

combination of factors was found to account for 39% of PPC variance. Ho *et al*[28] also investigated people who had been diagnosed as having HNC and found that the Hope scale, the Life Orientation Test-Revised (LOT-R), and the Post Traumatic Growth Inventory (PTGI) were all positively correlated. Results of regression analyses comparing hope and optimism in relation to PPC found that they contributed to a 25% variance of PPC as measure by the PTGI. However, only 'hope' was a significant individual indicator of PPC.

Lebel *et al*[30] investigated the impact of stigma as a predictor of benefit finding and although they report their results as a mixed group of Lung and HN cancer, they found that when controlled for stressful life events and matched for cancer status, stigma and benefit finding predicted well-being.

Quality of Life (QoL) is an important psychological factor, and Llewellyn *et al*[32] found that an increase in emotional growth was negatively related to the mental component summary (MCS) score. This indicates that higher levels of emotional growth are associated with poorer mental health-related QoL (HRQoL), but the study by Llewellyn *et al*[32] did not use a HRQoL measure specifically designed to assess HNC HRQoL factors. Harding[25] used a HNC specific measure of HRQoL and SF-12 (Table 1 & 2) and found that several subscales related to HNC and the Physical Component scale of the SF-12 were related to the development of PPC longitudinally.

Holtmaat et al[29] found that lower levels of depression as measured by that sub-scale on the hospital anxiety and depression scale combined with higher levels of social functioning resulted in greater PPC.

Impact of time since diagnosis or treatment completion

A key limitation of 6 of the 8 HNC studies is the short time frame over which data was collected[26,28-32]. One of those that looked at a greater time span only measured data once, so a trajectory of PPC developed could not be assessed[27]. To date, only Harding[25] has tried to determine a longitudinal trajectory of the development of PPC and further work is needed to examine associations with trajectories of PPC over time. Harding[25] goes some way to examine this, but was not able to differentiate if sub-groups with differing patterns of PPC development exist. Danhauer *et al*[16] yielded a BC model with six PPC trajectories. They found age, race, chemotherapy status, use of adaptive coping strategies, illness intrusiveness, depressive symptoms and social support, all differed among the groups. The Danhauer *et al*[15,16] work supports the idea that there are likely to be sub-groups within the HNC population. Greater numbers of people post HNC treatment are required to more fully understand differentiating factors.

Implications for clinicians

A recent systematic review[40] across cancer cohorts found that the vast majority of research has focused on BC, and that the majority of PPC research has focused on psychologcal variables, over looking cancer-realted variables. With the small number of HNC papers it is hard to draw comparisions with other cancer cohorts, due to the different gender, ages, rates of recurrance and 5-year surviaval times. However, the work of Danhauer[15,16] and Harding[25] suggest that their are similarilities in the development of PPC over time.

If PPC is going to be of benefit to health care professionals and service users, it needs to be harnessed as an intervention or elements of intervention packages. A meta-analysis assessed the relationship between intervention participation and PTG but failed to find any studies that included an outcome measure of PPC[41]. Roepke[41] suggests that there is a modest increase in PPC following intervention, but due to the limited research reported on the natural development and time course of PPC, it is possible that even this modest increase could be due to the passage of time. Future clinical practise needs to be mindful of these factors and include a measure of PPC in the development and delivery of interventions.

Conflict of interest statement

The author has no competing interests.

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