Role of Psychological Flexibility and Self-compassion in People on Home Parenteral Nutrition: Psychological, Line Care Adherence and Infection Outcomes

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Abstract

Background: Home parenteral nutrition (HPN) is an often life-saving nutritional treatment. However, it requires meticulous adherence to line care procedures and poses challenges to daily activities which can impact a person's quality of life (QOL) and psychological wellbeing. Less is understood about psychological processes that affect outcomes in HPN. Psychological flexibility (PF) and self-compassion (SC) have been identified as important processes in other chronic illness populations. This study aimed to examine the unique role of PF and SC in predicting psychological distress, wellbeing, QOL, line care adherence and line infections in adults on HPN.

Methods: The study was a cross-sectional, observational questionnaire design with data collected online through convenience sampling. Data collection was completed between May 2021 and February 2022; the study was advertised on online platforms and shared by relevant third sector organisations. Participants were adults currently on HPN. A measure of line care adherence was developed for the current study and the results of a principal components analysis indicated a final 9-item line care routine questionnaire.

Results: The sixty-six participants were primarily from the United Kingdom. Higher PF and SC were significantly correlated with the following outcomes in the predicted directions: lower psychological distress, higher wellbeing, higher QOL and increased line care adherence. Multiple linear regression models explained a significant proportion of the variance in all outcomes, except for line infections. PF was uniquely associated with lower total distress, lower anxiety, better wellbeing and higher QOL after controlling for SC, gender and age. Whereas SC was uniquely associated with lower total distress, depression and stress when controlling for PF, gender and age.

Conclusions: Interventions aimed at improving PF and SC may be beneficial to support the emotional wellbeing and QOL in individuals on HPN. Further research would benefit from prospective designs and consideration of objective measures of infection.

Keywords: home parenteral nutrition (HPN), psychological flexibility (PF), self-compassion (SC), quality of life (QOL), adherence

Background

Home parenteral nutrition (HPN) is a type of nutrition therapy provided through intravenous administration (central or peripherally inserted venous catheter) for patients living at home (Cederholm et al., 2017). HPN is most commonly used to treat patients with chronic intestinal failure (e.g., due to conditions such as short bowel syndrome or Crohn's disease), which means they are unable to absorb nutrients through their intestine. However, in some cases it is used to treat or prevent malnutrition in patients whose intestines are still functional (Pironi et al., 2020). Total parenteral nutrition (TPN) refers to when all nutritional needs are met through parenteral nutrition, and intravenous delivery is the only route via which nutrition is delivered. In contrast, partial parenteral nutrition (PPN) is when parenteral nutrition is provided in addition to any route other than intravenously (Cederholm et al., 2017). HPN is often a lifelong treatment, although it can be temporary depending on the underlying reason. It is a treatment that requires meticulous attention to line care practices, such as observing strict aseptic procedures when connecting and disconnecting the nutritional feed to prevent possibly life-threatening catheter-related bloodstream infections (CRBSI; Pironi et al., 2020).

Impact of Home Parenteral Nutrition

HPN poses many challenges to patients in terms of disruption to, or cessation of, daily activities including work, changes to social roles, and relationships. Infusions are generally given over a 10-to-12-hour period, often overnight, however this is dependent on the individual's treatment plan. Patients on HPN have been found to have lower quality of life (QOL) than the general population and individuals who have intestinal diseases not requiring HPN (Winkler, 2005). In particular, the physical functioning element of QOL appears lower in patients on HPN compared to the general population (Sowerbutts et al., 2021). In contrast, the impact of HPN on the psychological element of QOL is less clear. One study found psychological QOL worse compared to the general population (Blüthner et al., 2019), whereas other studies found QOL no different to the general population (Schliefert & Carey, 2013), or that it improved over time (Chambers et al., 2005).

Understanding the relationship between QOL and HPN is complicated, as it is difficult to differentiate between the impact of the physical effects of the underlying disease and the impact of HPN treatment itself. Persoon et al. (2005) found that despite individuals reporting multiple physical symptoms related to their underlying condition, it was psychosocial difficulties (such as changes in mood, restricted social lives, being dependant and lack of freedom) that participants expressed as having the largest negative impact on their daily lives. Huismann-de Waal et al. (2007) highlighted that

patients with chronic gastrointestinal problems adjusted better to HPN treatment than patients with acute gastrointestinal trauma. Similarly, people on lower volumes of HPN had better QOL, with decreased severity of underlying disease suggested as a potential reason for this finding (Sowerbutts et al., 2021). In their recent review of QOL in HPN, Sowerbutts et al. (2021) concluded that the certainty of evidence within this literature is poor, and therefore confidence in current understanding of QOL is limited.

HPN requires good adherence to the procedures around caring for one's line, to prevent complications including CRBSI. Therefore, understanding psychological processes that may influence adherence behaviours is important. Psychosocial factors including depression, lower QOL, social impairment and fatigue were associated with higher incidence of venous access device related complications, including CRBSI (Huisman-de Waal et al. 2011). In another study, diagnoses of anxiety and depression were more common in patients who experienced central line associated bloodstream infections, however, these variables were not retained as significant predictors in a regression model (Xue et al., 2020).

Depression and anxiety are commonly reported by individuals on HPN (Huisman-de Waal et al., 2007). In patients with chronic intestinal failure, 56% have been found to have clinical levels of anxiety or depression (Ablett et al., 2018) and in another sample, 41.7% were prescribed antidepressants for their mental health (Cloutier et al., 2021). The need for psychosocial support for patients has been recognised within these studies. Although QOL and wellbeing can be negatively impacted, many individuals on HPN normalise their responses and cope well (Winkler & Smith, 2014). Indeed, in qualitative studies individuals on HPN described the treatment as improving their QOL compared to the impact of their underlying condition prior to starting HPN, despite the restrictions it imposed (Tsang & Carey, 2015; Winkler et al. 2010). HPN has also been found to improve QOL in patients with cancer (e.g. Culine et al., 2014; Girke et al., 2016). Although various factors affecting QOL and wellbeing have been identified, there is a dearth of research examining potential protective or moderating factors, including psychological processes, that may affect QOL and distress outcomes in HPN populations. Understanding these potential processes is crucial for implementing support and service improvement. Psychological flexibility (PF) and self-compassion (SC) are relatively novel psychological processes that have been found to predict coping, adjustment, mental wellbeing and management in several chronic illness conditions (e.g. chronic pain, diabetes, cancer).

Psychological Flexibility

Psychological flexibility is the ability to be in the present moment with awareness and openness to one's experience, and to take action guided by one's values (Hayes et al., 2006). Increasing PF is the main aim of Acceptance and Commitment Therapy (ACT; Hayes et al., 2011a), and is underpinned by six processes: acceptance (awareness and willingness to experience distressing internal experiences),

cognitive defusion (distancing from thoughts and recognition that thoughts are not literal truth), contact with the present moment (e.g. through mindful non-judgemental experience), self-as-context (the perspective of being consciously aware of thinking and feeling, rather than the content of thoughts and emotions themselves), values (chosen qualities that provide meaning to one's life) and committed action (actions taken, informed by values; Hayes et al., 2006). Hayes et al. (2011b) described how these six processes can be grouped into three overarching processes: openness to experience, self-awareness and perspective taking, and valued action.

PF may be particularly relevant for people on HPN. For example, increased engagement with valued activities through committed action could potentially help mitigate the significant limitations arising from HPN. A willingness to be open to internal experiences through acceptance and defusion may also lessen the impact of psychological distress that can be an understandable response to the challenges associated with HPN. Although not yet explored in HPN populations, there is evidence of a role for PF within chronic illnesses.

Meta-analyses indicate that higher levels of PF are associated with better QOL and psychological outcomes, across populations of individuals with mental health conditions, physical health conditions and the general population with no reported mental or physical health conditions (Dochat et al., 2021; Hayes et al., 2006). More specifically, PF has been found to be associated with decreased rates of depression for patients with chronic kidney disease (Iida et al., 2020), lower diabetes related distress in Type 1 diabetes (Nicholas et al., 2021), and better wellbeing in Type 2 diabetes (Maor et al., 2021). PF also predicted increased life satisfaction and lower anxiety over four months within individuals with muscle disorders (Graham et al., 2016a). A recent review of meta-analyses concluded that ACT is an efficacious intervention across various presentations (Gloster et al., 2020). Within chronic pain populations, ACT interventions have improved functioning and distress (Du et al., 2021; Hann & McCracken, 2014; Hughes et al., 2017). A recent review also found improved outcomes for pain interference, disability, depression and QOL, with PF as a mediator (McCracken et al., 2022). Emerging research also suggests that ACT interventions are associated with improved outcomes across other long-term health conditions, although higher quality studies are required (Graham et al., 2016b). Furthermore, there is growing evidence of a relationship between PF and behavioural and physical health outcomes. For example, PF was associated with improved glycated haemoglobin (HbA1c) levels in Type 1 diabetes (Nicholas et al., 2021).

Self-compassion

Self-compassion (SC) is the ability to connect to one's suffering, with feelings of kindness and caring, along with an understanding and non-judgemental attitude towards oneself, whilst acknowledging suffering as part of humanity (Neff, 2003a). Neff (2003b) further defined six components of SC as: self-kindness vs. self-judgement, common humanity vs. isolation, and

mindfulness vs. overidentification. These facets of SC influence each other, whilst also being conceptually distinct (Neff 2003b). There are some plausible reasons SC may be important in HPN. Self-kindness may promote help-seeking, as well as improved self-care related to line care. Mindfulness aspects of SC might also be related to improved line care practices. SC may also help protect against self-criticism which could be easily triggered by the challenges and frustrations of adhering to a strict healthcare regime. A sense of common humanity could be related to increased social support, which has been shown to be an important factor influencing psychological distress within HPN (Ablett et al., 2018). More generally, SC has been found to mediate the positive relationship between perceived social support and psychological wellbeing (Wilson et al., 2020).

Across numerous studies in clinical and nonclinical samples, SC has been negatively associated with psychopathology (Muris et al., 2017), including depression, anxiety and stress (MacBeth & Gumley, 2012). Zessin et al. (2015) found SC had a causal relationship with greater wellbeing. Within chronic illness populations, SC was associated with decreased depression and diabetes related distress in Type 1 and Type 2 diabetes (Friis et al., 2016) and better QOL in individuals with celiac disease (Dowd & Jung, 2017). Furthermore, SC was associated with lower stress, directly and indirectly through greater use of adaptive coping and reduced use of maladaptive coping, in individuals with inflammatory bowel disease (IBD) and arthritis (Sirosis et al., 2015). A recent review concluded that SC-based interventions improved SC within patients with chronic physical health conditions, and increased SC was associated with improved wellbeing outcomes such as depression (Kiliç et al., 2021). There is also evidence of a relationship between SC on behavioural and physical health outcomes. SC predicted stricter dietary adherence within celiac disease (Dowd & Jung, 2017). SC also indirectly predicted dietary adherence, with self-regulatory efficacy (i.e., the confidence to self-manage their behaviours to achieve a desired outcome) mediating this relationship (Dowd & Jung, 2017). Similarly, to PF, SC has also been associated with improved glycated haemoglobin (HbA1c) levels in Type 1 and Type 2 diabetes (Friis et al., 2016).

Identifying potential psychological factors associated with QOL, distress, adherence to line care and medical outcomes (infections) would have important clinical implications. Positive findings would provide a rationale for treatment approaches underpinned by PF or SC, to support people on HPN to improve their QOL and health adherence behaviours. Better adherence is likely to result in fewer line infections, and therefore if higher levels of PF and SC help people better adhere to their line care this could have an indirect effect on infections. This could also have potential cost saving implications if infections requiring hospital care could be reduced (Buetti et al., 2022). To the author's knowledge, there have been no studies examining PF or SC within HPN populations.

Aims of the current study

The aim of the current study was to examine the unique role of PF and SC in predicting psychological distress (depression, anxiety and stress), wellbeing and QOL in individuals on HPN. The study also aimed to determine if PF and SC were associated with improved line care adherence and decreased rates of line infections requiring hospital admission. Psychological flexibility and SC were selected as predictive variables in the current study as they are processes that can be targeted in various psychological therapies, such as ACT and CFT. In addition, there is growing literature of their role within populations who have different physical health conditions, and that interventions aiming to improve PF and SC have demonstrated improved wellbeing outcomes, as discussed above. As there is some evidence that age and gender may also be associated with PF, SC, depression, anxiety, and QOL (Baxter et al., 2013; Bermejo-Franco et al., 2022; Edwards et al., 2019; Fryback et al., 2007; Salk et al., 2017; Souza & Hutz, 2016; Yarnell et al., 2015) it was deemed important to assess the contribution of PF and SC whilst controlling for these variables.

Hypothesis 1: higher PF would be independently associated with decreased distress, increased wellbeing and increased QOL. Hypothesis 2: higher SC would be independently associated with decreased distress, increased wellbeing and increased QOL. Hypothesis 3: higher PF would independently predict increased line care adherence and a lower number of infections. Hypothesis 4: SC would independently predict increased line care adherence and a lower number of infections.

Method

Study Design and procedure

The study was a cross-sectional, observational questionnaire design with data collected online through convenience sampling. Participants provided online consent, confirmed eligibility for the study, and accessed the study questionnaire through the Qualtrics platform (Qualtics, 2021). Data collection was completed between 17th May 2021 and 17th February 2022. The study questionnaire was advertised on online platforms including Facebook support groups and Reddit boards for individuals on parenteral nutrition, artificial nutrition or groups aimed at relevant health conditions (e.g. short bowel syndrome, IBD). It was also shared on Twitter. Crohn's and colitis third sector organisations in Australia, Canada, Portugal, United States and the United Kingdom (UK) shared the study on their websites and/or social media pages. The organisation PINTT (Patients on Intravenous and Naso-gastric Nutrition Treatment), based in the UK, shared the study in their newsletter and through email to members.

A service user receiving HPN was consulted throughout the study. They provided advice regarding questionnaire development and recruitment, assisted with study dissemination, and provided insight into living with HPN treatment. The study was approved by Cardiff University Ethics Committee (reference number: EC.20.04.14.6006A).

Participants

Participants were adults (18 years or older) and currently on HPN. Exclusion criteria for the study were individuals under 18 years of age, to ensure informed consent, and if the individual was not currently on HPN treatment.

Measures

Demographic information

Participants were asked to indicate their age, gender, country of residence, who they live with, their relationship status, and level of education. They were also asked what health condition led to them requiring HPN, how long they had been on HPN, how many days a week they were on HPN, and whether they received TPN or PPN.

Psychological Flexibility

PF was measured using the Comprehensive assessment of Acceptance and Commitment Therapy processes (CompACT; Francis et al., 2016). The questionnaire includes 23 items each rated on a 7-point scale (0=strongly disagree; 6=strongly agree), with 12 items reverse-scored. This questionnaire contains three subscales: openness to experience, behaviour awareness and valued action. Items include statements such as: "one of my big goals is to be free from painful emotions", "I rush through meaningful activities without being really attentive to them" and "I can identify the things that really matter to me in life and pursue them". A total score is obtained by summing all items, ranging from 0 to 138, with higher scores indicating greater PF. The scale and its three-factor structure has been evaluated as a reliable and valid measure of PF (Bayliss, 2018). Cronbach's alpha for the current study was 0.91.

Self-compassion

The Self-Compassion Scale short-form (SCS-SF; Raes et al., 2011) was used to measure SC. The questionnaire has been found to have a near perfect correlation with the original, long-form version and is recommended for research use (Neff, 2003b). It contains 12 items, six of which are reverse scored. Each question is rated on a 5-point scale (1=almost never; 5=almost always) and a total score is obtained by calculating a mean from all items following reverse scoring of negative items. Questions include statements such as "I try to see my failings as part of the human condition" and "I'm disapproving and judgmental about my own flaws and inadequacies". The SCS-SF has been found to have good internal consistency and is a valid and reliable measure of SC. It has previously been used within various chronic health samples (e.g. Sirois, 2020). In the current study, Cronbach's alpha was 0.88.

Psychological Distress

The Depression Anxiety Stress Scale short-form (DASS21; Henry & Crawford, 2005) is a general measure of psychological distress, which also measures three separate constructs: depression, anxiety and stress. It was developed based on the validated, 42-item version of the DASS (Lovibond and Lovibond, 1995). Each of the 21 items is rated on a 3-point scale (0=did not apply to me at all; 3=applied to me very much or most of the time over the past week). Higher scores indicate greater levels of distress. Scores are derived by summing the seven items for each subscale and then multiplying by two. The total score is obtained by a sum of the three subscales. Development and normative data for the DASS21 was carried out in non-clinical samples and it is well suited for research use. Internal reliability estimated by Cronbach's alpha ranged from to 0.82 to 0.93 for the three subscales and total score (Henry & Crawford, 2005). In the current study, Cronbach's alphas were: 0.95, 0.93, 0.87 and 0.88 for total distress, depression, anxiety and stress scales, respectively.

Wellbeing

Wellbeing was assessed using the Short Warwick Edinburgh Mental Wellbeing Scale (SWEMWBS; Stewart-Brown et al., 2009). The questionnaire includes seven positively phrased items, such as "I've been feeling optimistic about the future" rated on a 5-point scale (1=none of the time; 5=all of the time). The SWEMWBS is scored by first summing the scores for each of the seven items, and then transforming the total raw scores into metric scores using a conversion table. Scores range from 7 to 35, with higher scores indicating higher positive mental wellbeing. It has been validated in both the general adult population (Ng Fat et al., 2017) and clinical samples (Shah et al., 2021), and demonstrates good psychometric properties. Cronbach's alpha was 0.86 in the current study.

Quality of Life

The World Health Organization Quality of Life-bref (WHOQOL-BREF; Whoqol Group, 1998) was used to measure QOL. The questionnaire comprises of 24 items related to four domains: physical health (7 items), psychological health (6 items), social relationships (3 items) and environment (8 items), and two additional items pertaining to overall perception of QOL and health, which are not included in the domain scores. Item scores range from 1 to 5, and higher scores indicate better QOL. Domain scores are obtained by multiplying the average score of domain items by four, followed by conversion to a 0-100 scale to result in the final transformed score (WHO, 1996). The WHOQOL-BREF does not produce an overall total score. The WHOQOL-BREF has good to excellent psychometric properties, and it has been extensively evaluated across cultures and in many settings including within sick and well populations (Skevington et al., 2004). It has been recommended for use in research where a brief assessment of QOL is required. In the current study, Cronbach's alphas were: 0.84, 0.82, 0.69 and 0.82 for the physical, psychological, relationships and environment subscales, respectively.

Line care adherence

To the author's knowledge, there is no existing measure of line care adherence for individuals on HPN, therefore a questionnaire was developed for the current study. The questionnaire items were developed through review of other treatment adherence questionnaires, such as the asthma routines questionnaire (Fiese et al., 2005) and Morisky medication adherence questionnaire (Morisky et al., 1986), and clinical knowledge of a clinical psychologist working within an intestinal failure service. A service user on HPN also examined the original items and provided feedback on wording and relevancy to line care routine. Participants were asked to indicate their agreement to statements such as "it doesn't really matter if I miss out the occasional step when following my line care procedure" and "I can be careless about line care". Each of the items were rated on a 5-point Likert scale (1=strongly disagree; 5=strongly agree or 1=never; 5=always). A total score was calculated by summing the items after reverse coding negative questions. The original questionnaire consisted of 12 items, six related to thoughts and feelings and six related to behaviour. Following principal component analysis, nine items were retained, and all items loaded onto a single factor. Scores therefore ranged from 9 to 45, with higher scores indicating better line care adherence. Full details of the final 9-item version of the questionnaire used in analyses can be found in the appendix. As this questionnaire was developed for the current study, it has not been previously validated. Cronbach's alpha with the current sample was 0.80. Participants were also asked to indicate whether they currently, or in the past, received help looking after their line care at home, however these items were not part of the adherence score.

Line infections

Participants self-reported the number of line infections they had in the previous five years that required hospitalisation.

Sample size

There are no known studies that have used the variables of interest with the outcomes of the current study in this population, therefore in the absence of a previous effect size from the literature, a medium effect size was used in the power calculations. *A priori* power calculation for multiple regression analysis, completed using G*Power (Faul, et al. 2009), indicated for a medium effect size of Cohen's f^2 (0.15), statistical power level of 0.80 and p value of .05, a minimum sample size of 68 was required to detect significant unique contributions of PF and SC, on all outcomes. Subsequent power analyses were calculated based on up to four predictors, to include gender and age, indicating a minimum sample size of 85.

Statistical Analyses

Data were analysed using SPSS Statistics 27. The study hypotheses were tested by bivariate correlations and multiple linear regression analyses. Independent variables were entered into the

regression simultaneously, as there is currently not sufficient empirical or theoretical reasoning for whether PF or SC would be more predictive of the outcomes. Age and gender were entered into the regression analyses to control for their possible confounding effects on the outcomes.

Regression analyses were run following completion of assumption testing for normality, linearity, homoscedasticity, multicollinearity, and outliers, leverage values and influential points. These assumptions were met unless otherwise stated. When heteroscedasticity was found, robust standard errors and their associated confidence intervals were reported, rather than the standard error of the coefficients (Hayes & Cai, 2007). Where outliers were detected (by casewise diagnostics and deleted studentized residuals), these were examined, however they were retained as they were valid data points and did not have a large leverage value (assessed as less than 0.2; Huber, 1981) or large influence (measured by Cook's distance less than 1).

Results

Sample data

Participants that did not complete the full Qualtrics survey were excluded from the analysis. Twenty-six participants were excluded because they did not progress past informed consent (n = 11) or provided demographic information only (n = 15). Three participants answered only the first questionnaire (CompACT). One participant was excluded from analysis following examination of their responses, which indicated they were not receiving HPN. The final number of participants included was 66. There was one participant that did not identify as man or woman, and therefore this participant was excluded from any analyses that included gender (n = 65).

Data was checked for any missing values; no data was missing except for two participants who did not record their age. Mean substitution method was used for these two data points (Field, 2013).

Sample characteristics

Participants were predominantly women (71.21%) and from the UK (86.36%). The mean age was 47.78. Only 19.7% of participants lived alone, the remaining lived with others, and over half (59.09%) had a pet. Fifty percent of the sample were married. Highest level of education varied, with the majority having undertaken some form of post-secondary education (69.18%). Common reasons for receiving HPN included a shortened or damaged small bowel (e.g., short bowel syndrome or surgical complications), Crohn's disease, and disordered movement of the small bowel (e.g., Gastroparesis or Ehlers Danlos Syndrome). Most participants were on TPN (81.82%), for at least five or more days of the week (83.33%) and 72.72% had been on HPN for at least three years. About a third (28.79%) of participants indicated that they receive help with some aspect(s) of their line care. A t-test was run to determine if there was a difference in line care adherence scores between individuals receiving help and no help. Although individuals receiving no help with their line care had a slightly

higher mean line care adherence score (41.23 ± 4.28 vs. 39.58 ± 6.06), this difference was not statistically significant ($t(25.57) = 1.10$, $p = .28$). Full details of sample characteristics can be found in Tables 1 and 2.

Table 1

Sample characteristics (N = 66)

	Mean (SD) or *n* (%)
Age	49.78 (15.10)
Gender	
Women	47 (71.21%)
Men	18 (27.27%)
Did not identify as man or woman	1 (1.52%)
Country of residence	
United Kingdom	57 (86.36%)
Australia	3 (4.55%)
Ireland	1 (1.52%)
Netherlands	1 (1.52%)
Switzerland	1 (1.52%)
United States	3 (4.55%)
Living situation	
Alone	13 (19.70%)
With spouse or partner	33 (50%)
With family	16 (24.24%)
With others, not family	1 (1.52%)
Other	3 (4.55%)
Pet (yes)	39 (59.09%)
Marital status	
Single	21 (31.82%)
Married	33 (50%)
Living as married or cohabiting	4 (6.06%)

Separated	3 (4.55%)
Divorced	2 (3.03%)
Widowed	3 (4.55%)
Highest level of education	
Primary	1 (1.52%)
Secondary up to 16	11 (16.67%)
Completed secondary	9 (13.64%)
Undergraduate	26 (39.39%)
Postgraduate	11 (16.67%)
Trade/Vocational	8 (12.12%)
Reason for HPN[a]	
Blockage of the intestine	2 (3.03%)
A leak from a fistula or a false passage	1 (1.52%)
Disordered movement of the small bowel	15 (22.73%)
A shortened or otherwise damaged small bowel	23 (34.85%)
Crohn's disease (with no other information)	19 (28.79%)
Unable to classify[b]	6 (9.09%)
Number of years on HPN	
Less than 1 year	6 (9.09%)
1 year	4 (6.06%)
2 years	7 (10.61%)
3 years	10 (15.15%)
4 to 9 years	19 (28.79%)
10-19 years	11 (16.67%)
20 years or more	8 (12.12%)
Number of days on HPN/week	
2 days	1 (1.52%)
3 days	5 (7.58%)
4 days	5 (7.58%)
5 days	7 (10.61%)
6 days	9 (13.64%)
7 days	39 (59.09%)

HPN treatment	
Total (TPN)	54 (81.82%)
Partial (PPN)	10 (15.15%)
Unsure	2 (3.03%)
Currently receiving help with line care	19 (28.79%)

[a]Participants indicated their response as free text, which were classified into categories

[b]Reason stated could have fit into multiple categories (e.g. genetic condition, intestinal failure).

Table 2

Outcome measure scores (N = 66)

	Mean (SD)
Psychological Flexibility	80.45 (22.68)
Self-compassion	2.88 (0.79)
Psychological distress score	41.88 (28.78)
Wellbeing score	20.81 (3.45)
QOL	
Physical domain	44.60 (19.94)
Psychological domain	47.35 (17.21)
Social domain	50.13 (23.14)
Environmental domain	57.39 (17.61)
Line care adherence	40.74 (4.90)
Number of infections	1.43 (2.75)[a]

[a]Range = 0-16; further details of number of infections available in supplementary materials.

Principal Component Analysis

The Line Care Routine Questionnaire (LCRQ) was developed for the current study to assess for line care adherence. A principal components analysis (PCA) was run on the original 12-item questionnaire. The suitability of PCA was assessed prior to analysis. The overall Kaiser-Meyer-Olkin (KMO) measure was 0.73, considered 'middling' according to Kaiser (1974). There were two individual

KMO measures below <0.5, however these items were later removed based on the component matrix results. Bartlett's test of sphericity was statistically significant ($p < .001$), indicating that the data was likely factorizable.

Determination of how many factors to retain was completed by visual inspection of the scree plot (Cattell, 1966; supplementary information) and through parallel analysis. Percentile eigenvalues were generated for parallel analysis using Vivek et al. (2017) parallel engine. On these bases, only one factor was retained. No rotation was employed as all items loaded onto a single factor. Nine of the 12 items loaded onto this factor, using a 0.4 cut off value. Therefore, the three items that did not load were removed from the questionnaire. The component matrix can be found in supplementary information. The 9-item line care routine questionnaire was used for all subsequent analyses examining line care adherence.

Bivariate associations between study variables

PF, SC, distress, wellbeing, QOL and line care adherence were significantly intercorrelated with each other. In particular, PF and SC had a significant large correlation with each other ($r = .79$, $p < .01$). Conversely, number of line infections in the last five years was not correlated with any of the other variables (Table 3).

Table 3

Pearson product moment correlations between predictor and outcome variables

	Compact	SCS	DASS-21-D	DASS-21-A	DASS-21-S	DASS-21-T	SWEMWS	WHOQOL-Ph	WHOQOL-Ps	WHOQOL-R	WHOQOL-E	LCA†	Infection	Gender‡	Age
SCS	.79**	-													
DASS21-D	-.56**	-.60**	-												
DASS21-A	-.47**	-.39**	.53**	-											
DASS21-S	-.52**	-.56**	.82**	.60**	-										
DASS21-T	-.59**	-.59**	.91**	.79**	.92**	-									
SWEMWS	.58**	.53**	-.71**	-.40**	-.64**	-.67**	-								
WHOQOL-Ph	.34**	.17	-.55**	-.48**	-.54**	-.60**	.44**	-							

WHOQOL-Ps	.60**	.54**	-.80**	-.56**	-.70**	-.79**	.70**	.60**	-						
WHOQOL-R	.37**	.37**	-.55**	-.49**	-.57**	-.61**	.50**	.39**	.62**	-					
WHOQOL-E	.29*	.20	-.47**	-.56**	-.42**	-.55**	.43**	.65**	.64**	.47**	-				
LCA	.26*	.29*	-.37**	-.16	-.34**	-.34**	.13	.12	.42**	.24	.16	-			
Infection†	-.15	-.02	.08	-.24	.14	.07	-.07	-.09	-.01	.04	.16	-.10	-		
Gender‡	-.04	-.06	-.02	.07	-.01	.01	.08	-.25*	-.07	.06	-.02	.19	.22	-	
Age	.02	.004	-.12	-.17	-.25*	-.20	-.07	.33**	.23	.003	.18	-.14	-.24	-.30*	-

Note. CompACT = Comprehensive assessment of Acceptance and Commitment Therapy processes; SCS = SC; DASS21 = Depression Anxiety Stress Scale (D = depression, A = anxiety, S = stress subscales); SWEMWS = Short Warwick–Edinburgh Mental Wellbeing Scale; WHOQOL = World Health Organization Quality of Life questionnaire-Bref (Ph = physical, Ps = psychological; R = relationship, E = environment domain subscales); LCA = Line care adherence. n = 65.

†Spearman's rank correlation was computed due to infection failing parametric assumptions

‡Point-biserial correlation was computed due to gender being a dichotomous variable.

*p<.05, **p<.01

Multiple linear regression

A series of multiple linear regressions were conducted, each including the following predictors entered simultaneously into the model: age, gender, PF, and SC. The outcomes that were separately assessed were psychological distress and each of its subcomponents (depression, anxiety, and stress), wellbeing, the subcomponents of QOL (physical, psychological, relationship and environment), line care adherence, and line infections.

Psychological distress (depression, anxiety and stress)

The multiple regression model statistically significantly predicted distress as measured by the total DASS21, $F(4, 64) = 11.64$, $p < .001$, and explained 40% of the variance. PF ($B = -0.39$, $p = .05$), SC ($B = -12.36$, $p = .03$) and older age ($B = -0.42$, $p = .04$) were significant unique predictors of decreased distress (Table 4).

The multiple regression models for the subscales of the DASS21 were also significant (Table 4). The model explained 36% of the variance in depression scores and higher SC was the only independent predictor of lower depression ($B = -6.36$, $p = .01$). For anxiety, the model explained 20% of the

variance with PF as the only independent predictor of lower anxiety scores (B = -0.19, p = .02). The model explained 36% of the variance in stress scores. Both SC (B = -5.49, p =.01) and older age (B = -0.20, p = .01) uniquely predicted lower stress.

Table 4

Multiple regression results for total distress, depression, anxiety and stress

	Total distress		Depression[a]		Anxiety[a]		Stress	
	B (SE)	β	*B (SE)*	β	*B (SE)*	β	*B (SE)*	β
PF	-0.39 (0.20)*	-0.32*	-0.13 (0.08)	-0.24	-0.19 (0.08)*	-0.44*	-0.08 (0.07)	-0.18
SC	-12.36	-0.35*	-6.36	-0.42**	-0.52 (2.54)	-0.04	-5.49 (2.10)*	-0.43*
Gender	-5.57 (6.41)	-0.09	-2.76 (2.99)	-0.10	-0.01 (2.41)	0.00	-2.82 (2.38)	-0.13
Age	-0.42 (0.20)*	-0.22*	-0.12 (0.07)	-0.15	-0.10 (0.06)	-0.15	-0.20 (0.07)*	-0.28*
R^2	0.44***		0.40***		0.25**		0.40***	
Adj. R^2	0.40***		0.36***		0.20**		0.36***	
F	11.64***		9.98***		4.97**		10.08***	

Note. Model "Enter" method in SPSS Statistics. PF = Psychological Flexibility; SC = Self-compassion; B = unstandardized regression coefficients; *SE* = standard error of the coefficient; β = standardized coefficient; R^2 = coefficient of determination; Adj. R^2 = adjusted R^2.

[a]Robust standard error of the coefficient reported.

*p<.05; **p<.01; ***p<.001.

Wellbeing

The multiple regression model statistically significantly predicted wellbeing as measured by the SWEMWS, $F(4, 64) = 8.48$, $p < .001$, and explained 32% of the variance in scores. PF was the only independent predictor of increased wellbeing (B = 0.06, p = .02; Table 5).

Table 5

Multiple regression results for wellbeing

	Wellbeing	
	B (SE)	β
PF	0.06 (0.03)*	0.42*
SC	0.88 (0.74)	0.20
Gender	0.67 (0.84)	0.09
Age	-0.01 (0.03)	-0.06
R^2	0.36***	
Adj. R^2	0.32***	
F	8.48***	

Note. Model "Enter" method in SPSS Statistics. PF = Psychological Flexibility; SC = Self-compassion; *B* = unstandardized regression coefficients; *SE* = standard error of the coefficient; β = standardized coefficient; R^2 = coefficient of determination; Adj. R^2 = adjusted R^2.

*p<.05; ***p<.001

Quality of Life

The multiple regression models were statistically significant for both the physical and psychological domains of QOL, $F(4, 64) = 5.56$ $p < .001$ and $F(4, 64) = 11.16$, $p < .001$, respectfully. The model predicted 22% of the variance in the physical domain of QOL with PF ($B = 0.48$, $p < .01$) and older age ($B = 0.37$, $p = .02$) independently predicting increased QOL. PF ($B = 0.34$, $p < .01$) and older age ($B = 0.27$, $p = .03$) were also unique predictors for increased QOL on the psychological domain, and model predicted 39% of the variance in psychological QOL scores. The regression model was significant for the relationship domain, however none of the predictors were uniquely significant. The regression model did not significantly predict the environment domain of QOL (Table 6).

Table 6

	Physical		Psychological		Social		Environmental	
	B (SE)	β	*B (SE)*	β	*B (SE)*	β	*B (SE)*	β
PF	0.48	0.55**	0.34	0.45**	0.21 (0.20)	0.21	0.27 (0.15)	0.34
SC	-7.03 (4.56)	-0.28	4.10 (3.49)	0.19	5.91 (5.64)	0.20	-1.48 (4.40)	-0.07

Gender	-7.29 (5.17)	-0.16	1.02 (3.96)	0.03	4.26 (6.39)	0.08	1.76 (4.99)	0.05
Age	0.37 (0.37)*	0.27*	0.27 (0.12)*	0.23*	0.04 (0.20)	0.02	0.23 (0.15)	0.19
R^2	0.27***		0.43***		0.16*		0.12	
Adj. R^2	0.22***		0.39***		0.10*		0.06	
F	5.56***		11.16***		2.81*		2.06	

Multiple regression results for quality of life domains

Note. Model "Enter" method in SPSS Statistics. PF = Psychological Flexibility; SC = Self-compassion; *B* = unstandardized regression coefficients; *SE* = standard error of the coefficient; β = standardized coefficient; R^2 = coefficient of determination; Adj. R^2 = adjusted R^2.

*p<.05; **p<.01; ***p<.001

Line care adherence

The multiple regression model was significant for line care adherence, $F(4, 64) = 5.58$ $p < .001$, and accounted for 22% of the variance in adherence scores (Table 7). Only older age and gender ($B = 0.11$, $p < .01$) uniquely predicted adherence, with increased adherence in women ($B = 4.17$, $p < .01$).

Table 7

Multiple regression results for line care adherence

	Line care adherence[a]	
	B (SE)	β
PF	0.01 (0.04)	0.06
SC	1.66 (1.02)	0.27
Gender	4.17 (1.10)***	0.38***
Age	0.11 (0.04)**	0.34**
R^2	0.27***	
Adj. R^2	0.22***	

F	5.57***

Note. Model "Enter" method in SPSS Statistics. PF = Psychological Flexibility; SC = Self-compassion; *B* = unstandardized regression coefficients; *SE* = standard error of the coefficient; β = standardized coefficient; R^2 = coefficient of determination; Adj. R^2 = adjusted R^2.

[a]Robust standard error of the coefficient reported.

**p<.01; ***p<.001.

Line infections

The multiple regression model for number of line care infections was not significant (Table 8). This model violated the assumption of linearity, and therefore a series of exploratory quantile regression analyses were performed.

Table 8

Multiple regression results for line infections

	Line infections[a]	
	B (SE)	β
PF	-0.01 (0.02)	-0.10
SC	-0.43 (0.76)	-0.11
Gender	1.07 (0.49)	0.15
Age	-0.04 (0.02)	-0.20
R^2	0.12	
Adj. R^2	0.06	
F	2.01	

Note. Model "Enter" method in SPSS Statistics. PF = Psychological Flexibility; SC = Self-compassion; *B* = unstandardized regression coefficients; *SE* = standard error of the coefficient; β = standardized coefficient; R^2 = coefficient of determination; Adj. R^2 = adjusted R^2.

[a]Robust standard error of the coefficient reported.

Quantile regressions for line infections

Quantile regression analyses were performed to explore whether the predictor variables were associated with line infections at different quantiles of the outcome variable. Parameter estimates were computed for each 10th percentile. Neither of the predictors, PF, SC or covariates, age or gender, significantly predicted number of infections at any of the quantiles. Details can be found in supplementary information.

Discussion

This study aimed to test the association of PF and SC with psychological, behavioural and medical outcomes of individuals on HPN. Higher PF and SC were significantly correlated with the following outcomes in the predicted directions: lower psychological distress, higher wellbeing, higher QOL and increased line care adherence. The only variable which was not correlated with both PF and SC was number of infections, and SC was not correlated with the physical and emotional QOL domains. PF and SC were highly correlated with each other, consistent with previous research (e.g., Marshall & Brockman, 2016; Davey et al., 2020). The large correlation between PF and SC in the present study ($r = .79$) was very similar to the values observed in Kiliç et al. (2022).

Regression models included four predictors (age, gender, PF, and SC) and were significant for all psychological outcomes, except for environmental QOL. Regression analyses indicated that PF uniquely predicted lower total distress as measured by the DASS21, lower anxiety, higher wellbeing and higher physical and psychological QOL. SC also uniquely predicted lower total distress in the regression model. In contrast, SC was found to be a unique predictor for lower depression and lower stress, whereas PF was not. The finding that PF was associated with anxiety but not depression is consistent with the longitudinal findings of a previous study in muscle disorders, which found the same pattern prospectively, when controlling for baseline levels of anxiety, depression and life satisfaction (Graham et al., 2016a). Although in their cross-sectional analysis, PF was also independently associated with depression (Graham et al., 2016a).

Two other studies have examined PF and SC simultaneously within physical health populations. Consistent with the current study, Davey et al. (2020) found that SC uniquely predicted lower depression when age, gender, pain intensity, and PF were included in the model. However, they also found the openness facet of PF (in this case pain acceptance) to uniquely predict lower depression. Indeed, pain acceptance was consistently the facet of PF associated with better outcomes including pain inference and work and social adjustment, whereas the other two components of PF (awareness and engagement) were not significant (Davey et al., 2020). In a longitudinal study within Type 2 diabetes, PF independently predicted depression at six months (Kiliç et al., 2022). These findings somewhat conflict with those of the current study, where only SC was uniquely associated with

depression. The way depression is measured may be important. For instance, the aforementioned studies finding PF to predict lower depression utilised the Patient Health Questionnaire (PHQ-9; Kroenke et al., 2001) which includes somatic items. This may have distorted findings due to overlapping symptoms of the physical health condition and may be a possible explanation for the discrepancy in findings. Future studies might wish to carefully consider the measures that are used in health populations to measure mood. Consistent with the current study, within Type 2 diabetes PF independently predicted anxiety at six and 12 months, whereas SC did not (Kiliç et al., 2022). Kiliç et al. (2022) also found PF (and not SC) to uniquely predict QOL at 12-months. Collectively, these findings suggest that PF and SC are associated with distress and QOL in distinct ways, with PF being a somewhat more consistent predictor.

It could be hypothesised that PF's positive relationship with QOL could be a factor in the inconsistent findings in relation to QOL within HPN populations. For example, components of PF such as increased acceptance and viewing HPN as helpful in aiding the ability to live a meaningful life, may promote better QOL. These types of mediational analyses are an important area to explore in future studies. Some studies have started to explore possible mediators in the relationship between PF or SC and wellbeing outcomes. For example, Pyszkowska and Ronnlund (2021) examined the role of a balanced time perspective—an ability to mentally switch between orientations in time in an adaptive way—in mediating the positive relationship between each PF and SC, and wellbeing. They found that reduced deviations from a balanced time perspective did indeed mediate these relationships in a non-clinical, community sample, with Past Positive, Past Negative, and Present Fatalistic dimensions being most important (Pyszkowska & Ronnlund, 2021).

The current study also examined adherence behaviours and line infection outcomes. Although the regression model was significant, neither PF nor SC were independently associated with line care adherence. Harrison et al. (2021) had similar findings in relation to medication adherence, as PF was not uniquely associated with improved adherence to antiretroviral therapy in people with human immunodeficiency virus (HIV). Quantile regression results for the number of line infections were also not significant, indicating no association between PF or SC and line infections in the current sample.

Strengths and Limitations

This was the first study to examine PF and SC as predictors of distress, wellbeing, QOL, adherence and medical outcomes within individuals on HPN. The robustness of the analyses was strengthened by controlling for the possible confounding effects of age and gender, which have previously been shown to be associated with PF, SC and many of the outcomes. The use of the CompACT to measure PF is a strength of the current study, as it was developed to include all six underlying processes (Francis et al., 2016). In contrast, the Acceptance and Action Questionnaire-II (AAQ-II; Bond et al., 2011), the most commonly used questionnaire in ACT and PF studies, does not

encompass all six ACT processes and has been shown to have poor discriminative validity in relation to general distress (Tyndall et al., 2019; Wolgast, 2014).

The results from the current study need to be interpreted in the context of its limitations. A generic measure of QOL was used in the current study. Whilst this measure has been successfully used within health populations (Skevington & McCrate, 2011), generic measures also miss potential factors that are specific to individuals on HPN (Baxter et al., 2005). Measures specific to HPN treatment have been developed more recently, including: Home Parenteral Nutrition QOL questionnaire (HPN-QOL ; Baxter et al., 2008; Baxter et al., 2010), Home Parenteral Nutrition Patient Reported Outcome questionnaire (HPN-PROQ, Miller et al., 2017), New QOL questionnaire (New-QOL, Theilla et al., 2017), and Parenteral Nutrition Impact Questionnaire (PNIQ, Wilburn et al., 2018). For the current study, we were unable to obtain permissions to utilise the PNIQ or the HPN-QOL. The HPN-PROQ was not used as it was developed for use in clinical settings (Miller et al., 2017). It was also deemed advantageous to use a QOL measure with well-established psychometric properties, and consideration was given to response fatigue effects if two measures of QOL were to have been used. Nonetheless, future research would benefit from including one of the HPN specific QOL measures; the HPN-QOL tool in particular has been increasingly used (Chen et al., 2022).

As there was no existing measure of line care adherence, the LCRQ was developed for the current study. Cronbach's alpha of 0.8 indicated good reliability and PCA revealed that the measure loaded onto a single factor. However, validation studies of this measure are needed to determine if it is a suitable measure of line care adherence. If it is valid, it could be a useful way to screen for adherence behaviours, and to explore with patients any potential barriers to adherence. Assessing adherence to health-related behaviours is a challenge more widely, as subjective reporting is liable to social desirably and recall biases, and more likely to overestimate adherence (Stirratt et al., 2015).

The present study utilised self-reported number of line infections. A more objective measure of infections, such as medical records, would improve the validity of medical outcome data. However, this poses a separate challenge as due to the low number of people on HPN in any given hospital, this would likely need to be coordinated across multiple sites and was not feasible for the current study.

The analyses were based on cross-sectional data, therefore, temporal causation between the variables cannot be inferred. Future studies would benefit from longitudinal designs where PF, SC and the outcomes are assessed at various points over time. Despite extensive recruitment efforts, the required sample size was not achieved and therefore the study was potentially underpowered. This may have contributed to an underestimation of effect. Notwithstanding, we still found PF and SC to be uniquely associated with some of the outcomes. It is plausible that there could be other important confounding factors that were not controlled for in the current study, for example the underlying reason for HPN treatment and differing treatment regimes. These factors were not entered into the

current regression analyses because additional variables would have further decreased the power. However future research would benefit from exploring their potential influence. Effect sizes found in this study could be used as a guide for more precise sample size calculations in the future.

The study recruited internationally, although the Qualtrics questionnaire was only available in English. Results indicated that most respondents were from the UK, and therefore findings may not be generalisable beyond this population. The study was also subject to self-report bias. It is unknown whether there are differences between individuals choosing to take part in the study versus those who do not.

Finally, data collection occurred within the context of the Coronavirus (Covid-19) pandemic. Studies conducted during the pandemic indicate its negative impact on psychological wellbeing and QOL in people with gastrointestinal disorders such as IBD (Gavrilescu et al., 2022; Hayes et al., 2021; Sempere et al., 2022; Trindade & Ferreira, 2021). As some participants of the current study were likely on immunosuppressant medications for an underlying illness (e.g. Crohn's disease) this may have affected their adherence behaviours due to increased fear of infections or having to go into hospital. However, the impact of Covid-19 on adherence to line care is unknown. Findings related to medication adherence within IBD populations is mixed; with some reporting changes to their medication in response to the pandemic (El-Dallal et al., 2022) whereas Trindade & Ferreira (2021) found adherence to medication was high, and unrelated to fear of contracting Covid-19. Less has been examined about the impact of Covid-19 in relation to HPN populations specifically, however an international survey of professionals caring for individuals on HPN highlighted the adverse effect of the pandemic on supply shortages, reduced home care nurse availability, and psychological wellbeing (Allan et al., 2020). Allen et al. (2020) found that over 70% of patients reported anxiety, worry, concern, or apprehension, and over 20% reported negative thoughts or feelings related to pandemic related isolation or confinement. Furthermore, a recent UK survey of individuals on HPN found self-reported QOL was lower during the pandemic in comparison to pre-pandemic, high levels of anxiety and depression, and feelings of frustration around inconsistent information being received from difference sources (McCulloch et al., 2022). This survey also highlighted the impact of UK government advised shielding measures, involving enhanced social isolation and minimal social interaction, in which most of the participants surveyed completed. The survey indicated mixed findings regarding anxiety about the reduction of restrictions (McCulloch et al., 2022). Differential timings of Covid-19 restrictions in various regions over the time period of the current study could differentially impact on results.

Clinical Implications

The results of this study provide a rationale for future research into psychological interventions with individuals on HPN to support their emotional wellbeing and QOL. Therapeutic interventions that aim to increase PF and SC, such as third wave cognitive behaviour therapy (CBT) approaches may be particularly appropriate. Third wave CBT interventions such as ACT and compassion-based approaches (e.g. compassion focussed therapy [CFT, Gilbert, 2014] or mindful self-compassion [MSC, Neff & Germer, 2013]) may be differentially effective depending on the presenting difficulty. For example, the tentative findings from the present study suggest that improving PF could positively impact those experiencing anxiety and lower QOL, whereas targeting SC may be more helpful for those with depression. However, the results from the current study need to be replicated, preferably employing longitudinal designs, to further understand the unique contributions of PF and SC.

There are encouraging findings on the applicability of ACT and CFT in other health conditions. For example, a recent randomised control trial (RCT) comparing a self-help ACT intervention to usual care found ACT improved QOL, mood, impact of symptoms on functioning, and the acceptance and committed action components of psychological flexibility, for individuals with muscle diseases (Rose et al., 2022). ACT was also associated with decreased stress and depression in people with IBD compared to treatment as usual (Wynne et al., 2019). Interestingly, this study found no difference in anxiety. This contrasts with what may be expected based on the current study's finding of PF's independent association with anxiety. Psychological flexibility also significantly improved over the 8-week intervention and was maintained at 20 weeks; these positive changes in psychological flexibility were significantly correlated with the reduction in stress (Wynne et al., 2019).

Kilic et al. (2022) proposed that due to the degree of correlation between PF and SC, interventions underpinned by either construct may improve the other as well. For example, one RCT determined an ACT-based workshop significantly improved self-compassion compared to a waitlist control condition; furthermore, this change was mediated by psychological flexibility (Yadavaia et al., 2014). More recently, a study comparing the efficacy of brief, online ACT and CFT interventions found both were effective in reducing illness-related shame and uncompassionate self-responding, as well as increased valued living, within a chronic illness sample, with the most common illness being IBD (Carvalho et al., 2022).

Conclusions

This study sought to understand the independent associations of PF and SC with QOL, wellbeing, distress, line care adherence and infections within people on HPN. Findings indicated that PF and SC were strongly correlated to each other and were correlated with all outcomes other than number of infections. Whilst both PF and SC were independent contributors to the regression models, this differed across outcomes. Specifically, PF predicted total distress, anxiety, wellbeing and QOL, whereas SC predicted total distress, depression and stress. A measure for line care adherence was also

developed for the current study, although validation studies are required before any conclusions can be made regarding its appropriateness for future use. This study has important limitations, and findings should be confirmed, particularly with longitudinal designs. However, it provides an encouraging rationale for exploring psychological therapies to improve emotional wellbeing and QOL amongst people on HPN.

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Appendix:

Line Care Routine Questionnaire

Screening Questions:

The following questions will ask you about your line care routine:

1. Are you currently having help looking after your line care at home (e.g. from family or home care staff)?

Yes No

2. In the past have you received help with looking after your line care when you are at home?

Never Rarely Sometimes Most of the time Always

Line care adherence questions:

Now thinking about when you are carrying out your own line care at home, please indicate how much you agree with the following statements:

Options:

1 = strongly disagree 2 = disagree 3 = neither agree nor disagree

4 = agree 5 = strongly agree

1. *It doesn't really matter if I miss out the occasional step when following my line care procedure*
2. *If someone hasn't had a recent line infection, then they don't need to be as strict with their line care*
3. *Sometimes I cannot be bothered to care for my line*
4. *I find it difficult to be honest with medical professionals about how well I'm looking after my line*

Options:

1 = Never 2 = Rarely 3 = Sometimes 4 = Most of the time 5 = Always

5. I follow a strict series of steps when connecting/disconnecting my line
6. *I am not as careful with my line care when I am feeling down or tired, or if am busy*
7. *I can be careless about line care*
8. *I miss out a step or two when connecting/disconnecting my line*
9. *I engage in activities that might accidentally lead to a line infection*

Scoring:

Sum all items (*reverse-scored items in italics)*

Higher scores indicate higher line care adherence.