



Admiral Nurse services

Measuring carer quality of life using
the Adult Carer Quality of Life tool

Analysis of Adult Carer Quality of Life questionnaires administered between February 2015 – December 2018

Introduction

To help us measure whether Admiral Nurse interventions work in providing support for carers we carried out an analysis of completed Adult Carer Quality of Life questionnaires* from carers receiving Admiral Nurse support.

The Adult Carer Quality of Life (AC-QoL) is a validated tool measuring overall quality of life for adult carers, and subscale scores for eight domains of quality of life – support for caring; caring choice; caring stress; money matters; personal growth; sense of value; ability to care; and carer satisfaction.

It can be used before and after interventions to measure change and the impact of support. A number of our Admiral Nurse services use this tool during their clinical interventions with carers of people living with dementia – as part of their initial assessment and at additional points during their clinical intervention.

We analysed every AC-QoL with at least one repeated measure (which had been completed between February 2015 and December 2018), across 26 Admiral Nurse services in England and Wales. Our total sample comprised of 442 repeated measures, relating to work carried out in the community.

Data collection and sample

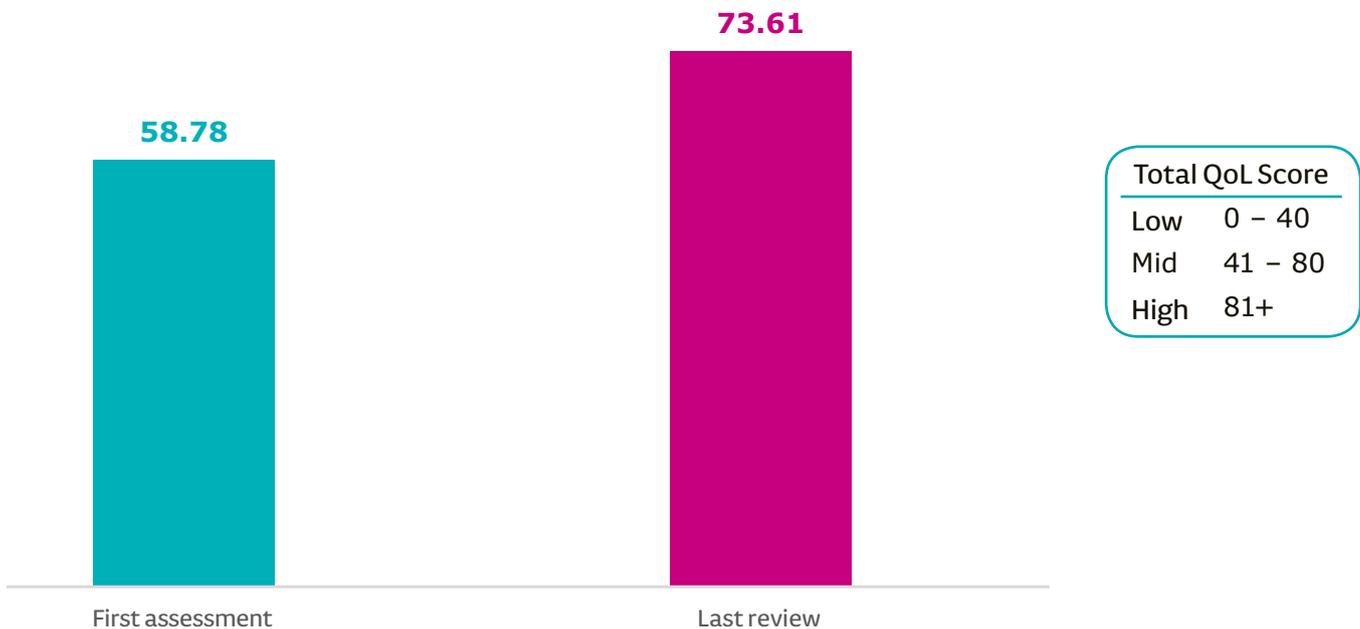
The data was recorded by our Admiral Nurses on our clinical system (WANDA) and includes a variety of clinical contacts, collected by many different nurses, at varying points throughout the Admiral Nurse intervention. There were no specific exclusion or inclusion criteria for records included in our sample, other than that the person is in the care of an Admiral Nurse service and that they have complete AC-QoLs with at least one repeated measure.

In our total sample of carers with completed AC-QoLs (n=442):

- **61%** are female
- **50%** were aged over 75

* Elwick, H., Joseph, S., Becker, S. & Becker, F. (2010) Manual for the Adult Carer Quality of Life Questionnaire (AC-QoL). London: The Princess Royal Trust for Carers.

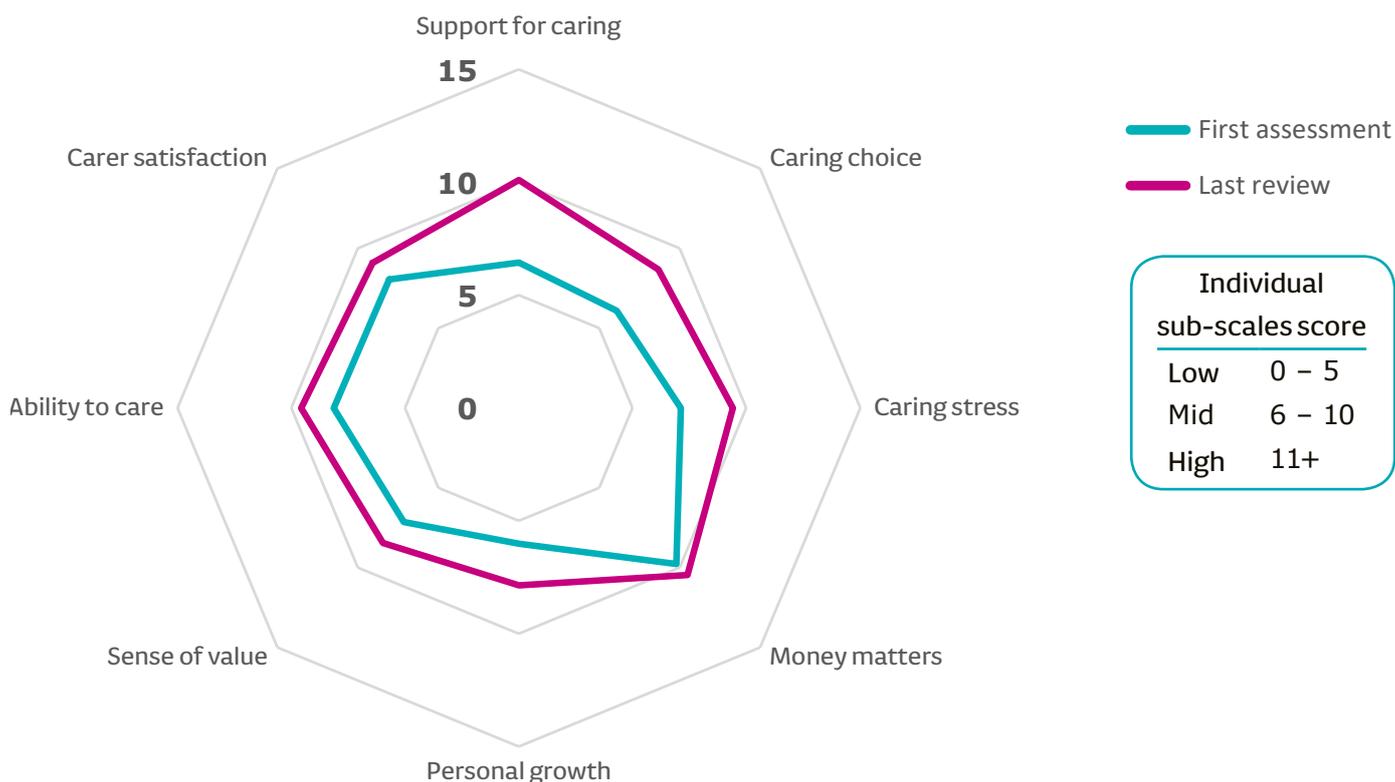
Total quality of life Score analysis



- We examined **442** completed AC-QoL from 439 clients of Admiral Nurse services (three people were re-tested upon re-referral).
- Overall the AC-QoL mean total quality of life score increased from **58.78** to **73.61**, bringing the average client closer to the high range of quality of life.
- This change is **statistically significant** (meaning it is highly unlikely to be due to chance).
- To check for this, we conducted two types of tests, as we noticed that the distribution was slightly skewed by a single case (which had a remarkably lower score than the rest of the sample). We ran a parametric test (the Paired Sample T-test) on the normalised sample, excluding that single case. The test showed a significant change ($p < .001$). However, we also checked whether this would still be true once the outlier was included back in the sample. For this second analysis we used a non-parametric test (the Wilcoxon Signed Ranks test), to take the skewed distribution into account, and this too showed a significant change ($p < .001$).
- We also ran a test to see how large the size of the change was between pre and post assessment (the so called ‘effect size’) from a statistical point of view. The effect size was **medium to large** for the overall sample (for the Wilcoxon test, $r = -0.486$) and **large** for the trimmed sample (for the Paired t-test, $d = 0.868$).
- This effect size was the result of most of our clients’ scores improving, and notably by a considerable margin for many.

AC-QoL sub-scales

Score analysis



Subscale	First assessment (mean score)	Last review (mean score)	Wilcoxon ranked sign test
Support for caring	6.44	10.09	p<.001
Caring choice	6.08	8.68	p<.001
Caring stress	7.12	9.41	p<.001
Money matters	9.78	10.47	p<.001
Personal growth	6.01	7.85	p<.001
Sense of value	7.15	8.45	p<.001
Ability to care	8.14	9.57	p<.001
Carer satisfaction	8.06	9.09	p<.001

We conducted related samples Wilcoxon tests for each sub-scale, finding that **all 8** sub-scales showed **significant positive change** between the pre and post mean score.

The change in subscale scores between first and last review was greatest for ‘support for caring’, ‘caring choice’ and ‘caring stress’.

Conclusions

The analysis of AC-QoL scores to measure whether Admiral Nurse interventions work in providing support for carers suggests that the interventions are having a positive effect:

1. Admiral Nursing interventions are potentially associated with statistically significant changes in quality of life for family carers, with a medium to large effect size.
2. Admiral Nursing interventions are potentially associated with a positive impact across all eight sub-scales on the AC-QoL measure.
3. The effect size (i.e. the amount of change) can be seen in the large proportion of family carers that report an improvement, and in the considerable scale of that improvement, across the sample.

Limitations of this process and learnings for the future

The AC-QoL questionnaire may or may not have been completed with the nurse present.

Length of time between the first and repeated measurements varied, from 3 to 889 days. The vast majority (92%) of repeated measure were within a calendar year.

There are only two measurements used in our study: the first and last. Therefore we are using two statistical tests (the related samples t-test and the Wilcoxon Ranked Sign Test, depending on the distribution of the data) to check whether the change in the total quality of life score and in the subscales is significant or is due to chance.

There is no control group for this cohort study (a group that did not receive an Admiral Nurse intervention), hence we cannot conduct deeper analysis of trends outside of the client group to compare with a cohort that did not receive the Admiral Nurse intervention.

We cannot explore the role of other possible factors which could influence the quality of life of family carers' (e.g. depression, level of complexity when presenting to the team, stage of dementia of the person cared for, changes in the dementia journey etc.) as this information cannot be drawn from the database or has not been collected.