367

Efficient extended follow-up and its effects on patient questionnaire responses: lessons from the EQUAL study in the UK

Dr Emer Gates[1], Dr Barnaby Hole[2], Dr Samantha Hayward[1], Dr Fergus Caskey[2], The Equal Investigators[2]
[1]North Bristol NHS Trust, Bristol, United Kingdom, [2]University of Bristol, Bristol, United Kingdom

Introduction
The EQUAL study is a European prospective cohort study in elderly patients with chronic kidney disease stage 4, aiming to understand when dialysis should be initiated. 1479 patients were recruited, including 507 from UK centres[1]. Research nurse-led "traditional" follow-up ceased after 4 years in the UK, in which patients answered validated questionnaires: Dialysis Symptom Index, SF-36, and three others. This was converted to "efficient" follow-up with postage from the UK Renal Registry. Condensed versions of the Dialysis Symptom Index and SF-36 were developed into a questionnaire of 80 questions over 8 pages for efficient follow-up, compared to 102 questions over 11 pages in traditional follow-up. Here we describe response and error rates of questionnaires.

Methods
In traditional follow-up, local sites administered patient questionnaires in research clinics three- to six-monthly. After receiving consent for efficient follow-up, questionnaires were administered by post from the UK Renal Registry. Questionnaire response and error rates for six-monthly traditional follow-up and the first efficient follow-up are presented here for UK participants who responded to efficient follow-up. Errors are defined as: a missing answer; missed double-page spread of questions; duplication of answers; and crossing answers out.

Results
Of 83 patients who consented to efficient follow-up, 60 returned a completed questionnaire. Patients were recruited to EQUAL over 4 years and therefore traditional follow-up ranged from 12 to 48 months, average 32.5 months. Response rates across traditional follow-up (Figure 1) steadily fell from 54/59 (91.5%) patients to 0/2 (0%) patients at 48 months. Efficient follow-up was on average 28 months after the last traditional follow-up, and 60/83 (72.3%) patients responded. 51/60 (85%) patients filled in the questionnaire without assistance.

Average error rate per questionnaire increased with time in traditional follow-up (102 questions) from 4.7/102 (4.6%) to 12.5/102 (12.3%) at 42 months. In efficient follow-up, 315/4800 (6.6%) errors were made in 60 questionnaires of 80 questions each. Common errors included patients missing individual questions in 143/315 (45.4% of errors), or missing double-spread pages of questions in 65/315 (20.6%) errors. In 73/315 (23.2%) errors, patients made errors in the Dialysis Symptom Index questions, ticking "no" to experiencing a symptom alongside a quantifier indicating "not at all bothered" by the symptom.

Discussion
Evidence demonstrated possible follow-up fatigue in traditional follow-up. The efficient follow-up questionnaire was shorter than in traditional follow-up, so our comparison has limitations; but increased response rates suggest that sending questionnaires back via post may be more acceptable to patients than attending a research clinic.

The error rate did not increase in efficient follow-up, however mistakes were seen that are less likely with research nurse delivery, such as skipped double-spread pages. Errors in the Dialysis Symptom Index

highlights the importance of choosing appropriate questionnaires for patients, especially as the majority of patients filled in questionnaires without assistance from family. This study adds evidence to considering postage of research questionnaires as a useful form of follow-up, which may make research participation more accessible. Further work will seek to verify these findings with all 507 patients in traditional follow-up.