

GilenyaConnect: Patient and healthcare professional satisfaction feedback

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Background

Fingolimod, a sphingosine-1-phosphate receptor modulator, is a disease modifying therapy (DMT) approved for the treatment of relapsing–remitting multiple sclerosis (RRMS).¹ Once-daily oral treatment with fingolimod is associated with reduced frequency of clinical exacerbations and delayed accumulation of physical disability.¹

With the first dose of fingolimod, all patients should undergo First Dose Observation (FDO) for the first 6 hours post-initiation for the signs and symptoms of bradycardia.¹ This includes hourly heart rate and blood pressure measurements, and continuous (real-time) electrocardiogram (ECG) monitoring.¹ A monitoring schedule during the first year (First Year Monitoring, FYM) is also recommended. This includes the assessment of liver function at Months 1, 3, 6, 9 and 12, and full blood count at Month 3.¹

To provide UK centres with specialist nurse support for FDO, Novartis initiated an FDO support programme in 2012. This was extended to include support for FYM and pre-initiation assessments (liver function, full blood count, ECG and blood pressure) in 2017 and 2018, respectively. The support programme is now called GilenyaConnect (GC) and currently around 40 centres in the UK offer at least one of the three services, with over 3,000 patients having used the service to date.

Aim

To evaluate the quality and value of the GC service provided by specialist nurses at FDO and FYM appointments from a patient and healthcare professional (HCP) perspective.

Methods

Patients with RRMS enrolled in the GC programme were asked to complete structured questionnaires (print format) designed to evaluate the service provided at FDO and FYM appointments (1=very poor; 5=excellent). The questionnaires, asked after the FDO appointment and FYM programme (after Year 1), were designed to assess GC nurses' knowledge, availability and patient support. Questionnaires were also given to HCPs from centres enrolled in the programme. Qualitative feedback on the GC service from the University Hospital Southampton NHS Foundation Trust is included. Feedback was collected between July 2017 and August 2018.

Summary and conclusions

- The GilenyaConnect programme provides UK centres with specialist nurse support for fingolimod pre-initiation, First Dose Observation (FDO) and First Year Monitoring (FYM) visits**
- Over 90% of patients consider the GilenyaConnect service provided as FDO and FYM as 'excellent'**
- 100% of patients recommend GilenyaConnect to other patients with relapsing–remitting multiple sclerosis (RRMS) prescribed with fingolimod**
- The majority of HCPs were totally satisfied with the quality of contact received as part of the GilenyaConnect service**
- HCPs highlighted that this programme helped MS centres to effectively manage workload and provided a safety net when and where patients required it**

Experience from the University Hospital Southampton NHS Foundation Trust

The GC service(s) we use

We have access to the full service of the GC programme. At FDO, the GC nurse is introduced to the patient; together they set expectations and agree on the schedule of visits and phone calls for FYM. During their first year on fingolimod, the GC service offers patients a face-to-face nurse review, phlebotomy service and scheduled telephone reviews.

Our experience with the service

We had a rough start to the programme due to staff changes and shortages from the PSP programme. Nevertheless, these issues were immediately discussed with all parties involved and subsequently resolved. By having a designated GC nurse, we were able to guarantee continuity of care from FDO to discharge from the GC service, both from the patients' and the MS nurses' point of view.

The impact of the GC service on my...

Patients: Staying connected with the GC nurse improved patient experience and safety.

Team: The GC service freed MS nurses' time, and allowed them to focus on monitoring MS patients and manage their symptoms more attentively. This is possible because we are confident that the patients under the GC service are very well looked after.

Centre: Overall, it helped manage caseloads.

Results

Patient feedback on GC FDO service²

- Of the 85 patients who underwent FDO, questionnaire feedback was collected from 41 patients
- 96.1% of patients rated the overall FDO service provided by GC nurses as 'excellent'. Feedback on specific components of the FDO service is summarised in Figure 1

Patient feedback on GC FYM service²

- Of the 119 patients enrolled for FYM through the GC programme, feedback was collected from 11 patients
- The overall FYM service provided by GC nurses was rated as 'excellent' by 90.9% of patients. Feedback on specific components of the FYM service is summarised in Figure 2
- 100% of patients** who left messages for their GC nurse received a response **'Within 24 hours'**

HCP feedback on the GC service²

- A total of 12 HCPs from centres participating in the GC programme completed questionnaires. Out of these, 16.7% were MS coordinators/operation leads and 83.3% were MS nurse specialists
- HCP feedback on specific components of the GC service is summarised in Figure 3
- 63.6% of HCPs received a response from GC nurses 'Within 24 hours'
- 75.0% of HCPs were 'Totally satisfied' with the quality of contact received as part of the service

100% of patients recommend GilenyaConnect to other patients with RRMS prescribed fingolimod

Figure 1 | Patient feedback on the service received during FDO (n = 41)²

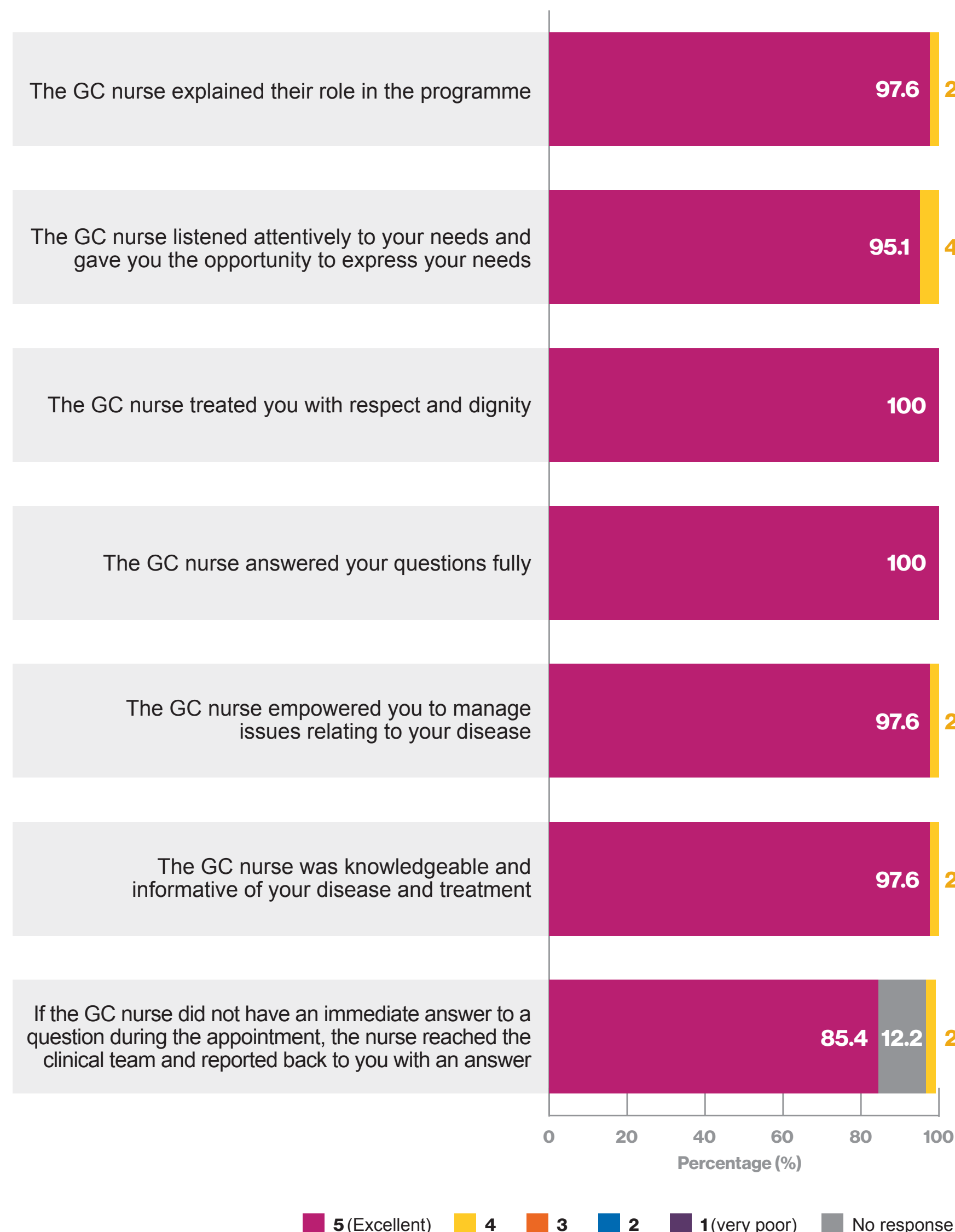


Figure 2 | Patient feedback on the service received during FYM (n = 11)²

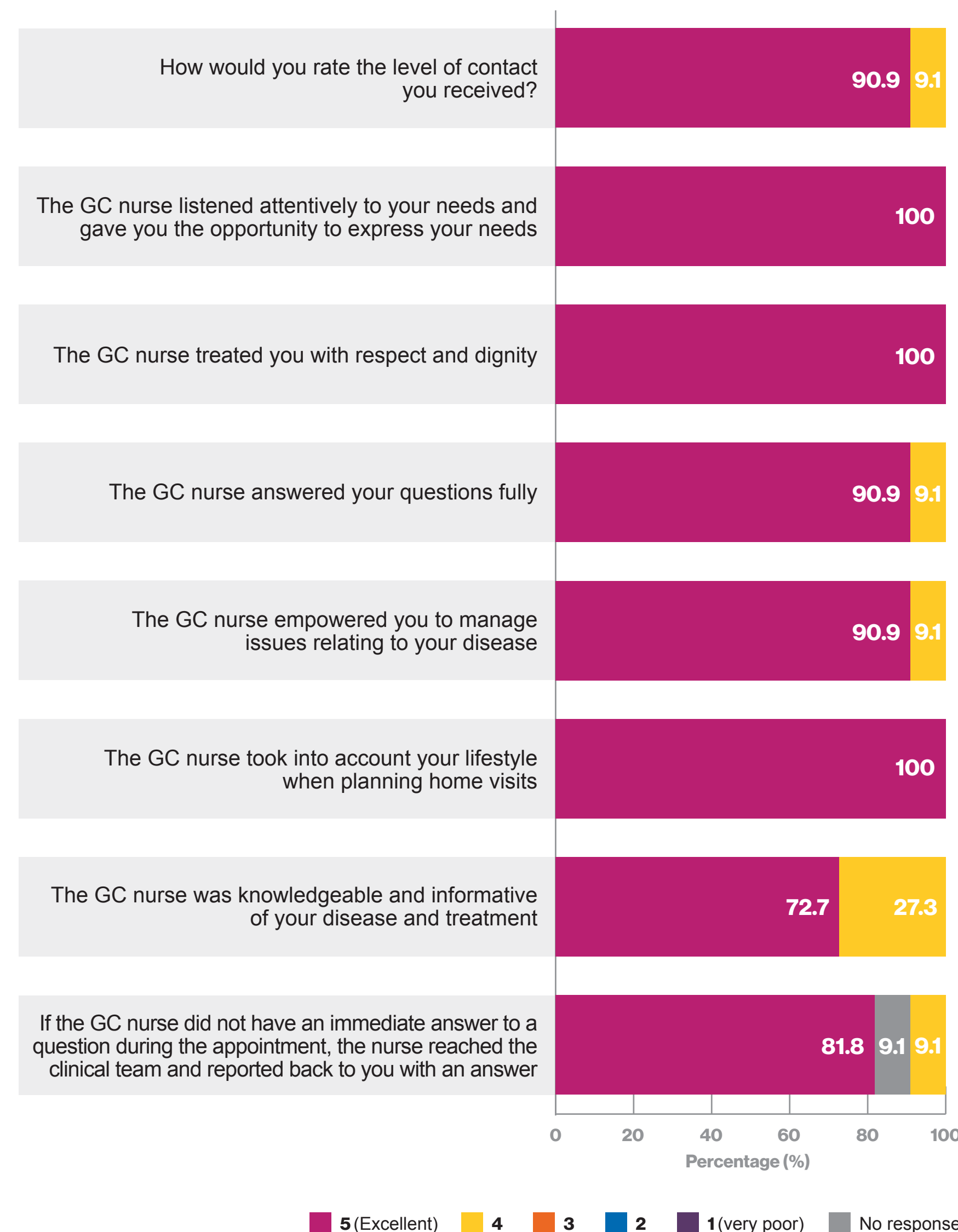


Figure 3 | HCP feedback on the GC service (n = 12)²

