Tidsskriftet Tidsskrift for Den norske legeforening

Finding the right answers begins with the right questions

EDITORIAL

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The author has completed the ICMJE form and declares no conflicts of interest.

Patient-reported experiences: What do we *want* to know, what do we *get* to know, and how do we use the answers?

The experiences of patients and their families are important supplements to other quality indicators in the health service (1). A PubMed search for 'patient-reported experience outcomes' shows an exponential increase in the number of articles on this topic over the last ten years. Norway was an early starter (2), and the website of the Norwegian Institute of Public Health provides several generic questionnaires that can be used to investigate the experiences of patients and their families (3). The results of studies using these questionnaires show that Norwegian patients and families are largely satisfied (4–6). Such results are likely to be read with satisfaction by health administrators and politicians.

The experiences of parents of children with Down syndrome, as reported in a survey published in this issue of the Journal of the Norwegian Medical Association, modifies this picture (7). In contrast to the studies referred to above, which ask general questions after a hospital stay or a visit to an outpatient clinic, Stefferud and colleagues ask about the follow-up of the children, and their questions relate specifically to children with Down syndrome. The authors find that only half of 161 parents were satisfied with the follow-up by the paediatrician or the child habilitation service. The parents were least satisfied with the follow-up of issues related to sleep, puberty and mental disorders, and most satisfied with the follow-up of congenital heart defects, vision and endocrine disorders. A very worrying finding is that nearly one of every five parents considered that the diagnosis of Down syndrome had led to lack of treatment on one or more occasions.

The authors did not use a validated questionnaire. Since the sample includes only about 12 % of all persons with Down syndrome in the actual age group and since the responses were collected from an interest group through an online survey, there is a considerable risk of selection bias. It would thus be interesting to learn whether the habilitation services and paediatric departments recognise the picture outlined in these results. If they do, the results suggest that there is potential for several other improvements as well.

In a report from 2020 (4), presented under the heading 'Norwegian patients are generally satisfied with their care during hospitalisation' (5), issues pertaining to discharge and coordination between health providers received the lowest scores; around 60 on a scale from 0 (poorest) to 100 (best). Moreover, patients who assessed their own health as fairly good or poor were less satisfied than patients who deemed their own health to be very good or excellent. Older patients were less satisfied than younger ones. In another study, published in 2021, the authors found that 97 per cent of the families were satisfied with the interdisciplinary assessment of their children at the child habilitation centres in the counties of Finnmark and Troms (6). However, they also found that a relatively high number of families were less satisfied with the coordination of the services. Taken together, these suggest that patients with complex needs are less satisfied with the healthcare system than the average patient after a hospital stay or a visit at an outpatient clinic.

> ***«It would indeed be useful if patient-reported experiences were routinely included in in the evaluation of both minor and major changes in the healthcare system»***

It would indeed be useful if patient-reported experiences were routinely included in the evaluation of both minor and major changes in the healthcare system. However, how suitable are the available generic questionnaires for this purpose? A systematic review from 2019 found that only two out of 88 questionnaires encompassed the healthcare system, and only four of them had a documented ability to measure changes after interventions (8). The ability to measure change is essential when a questionnaire is used to measure the effect of interventions. Nor should there be a ceiling effect (i.e. that a high number of respondents give the highest score), as was the case for the generic questionnaire used in the study in Troms and Finnmark (6).

In recent years, the Norwegian healthcare system has seen several major and minor reforms that may have affected, or will affect patient reported experiences. Examples of major reforms are the so-called Coordination Reform, aiming to improve the collaboration between hospitals and primary care; another is the reduction in the number of small hospitals in order ensure broad competence at fewer, but larger hospitals. Even though these major reorganisations are likely to be irreversible, patient experiences can still be useful for future planning of similar major reforms. Closures of small maternity wards and shorter hospitalisation times in post-natal units are examples of minor reorganisations. It is probably easier to explain that better clinical quality outweighs any negative patient experiences in the case of the former changes than it is in the latter.

Irrespective of the purposes for which one wants to use patient-reported experiences, the study by Stefferud and colleagues indicates that generic questionnaires should be supplemented with targeted questions as well as questions that more widely encompass the healthcare system. Although the answers may not be as pleasant, it is necessary if we are not to miss out on important information.

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Publisert: 21 September 2021. Tidsskr Nor Legeforen. DOI: 10.4045/tidsskr.21.0553