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FULL REPORT

Part 2 - Development and validation of quality indicators on aftercare for patients with AUD: a Delphi study



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Voorwoord

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Background

Alcohol use is a major cause of morbidity and mortality. According to a recent WHO-report the use of alcohol is a component cause of more than 200 disease and injury conditions in individuals, most notably alcohol dependence, liver cirrhosis, cancers and injuries (1). Mortality attributed to alcohol use is estimated at 1 in 7 deaths for men and 1 in 13 deaths for women (2).

In Belgium according to the Belgian health survey 10% of the Belgian population has an alcohol use disorder (AUD) (based on the CAGE-criteria) and Rehm et al.8 state that 5.4% of Belgian men and 1.9% of Belgian women aged 18–64 were affected with alcohol dependence (3-4).

In addiction medicine there is now a broad support for AUDs to be a chronic health problem, presenting many similarities with other chronic diseases in heritability, course, risk of relapse, and response to treatment (5). Yet, in contrast to other chronic diseases, the condition is extremely undertreated. A European study (including Belgium) found that only 8% of persons with an alcohol problem had consulted some form of professional assistance in the past year (6).

This treatment gap is the result of 2 major processes. First, it has been shown that there is a long delay before individuals with AUD seek help. Multiple barriers at the level of the individuals with an AUD, the health professionals and also the socio-economic context have been identified (7-8).

Second, many individuals entering treatment are discharged or drop out prematurely. The reasons for this are multiple. Current care for patients with AUDs is often inadequate and based upon practices with little or no evidence of effectiveness (5, 9-11). In addition, it relies heavily on an acute treatment model, providing detoxification programs, sometimes followed by specialty treatment rehabilitation programs, but without proactive efforts to ensure continuity of care thereafter (5). Finally, there is no integration of care. Medical treatment, mental health care and substance abuse programs are often provided separately, and different healthcare settings (inpatient, outpatient and partial hospitalization) generally function independently.

In continuing care for patients with AUD, multiple isolated continuing care interventions have been described in a wide variety of formats and modalities (10, 12). Nevertheless, fully integrated care programs (ICP) have never been developed (13).

Objectives

The final aim of the Belgian ICARUS project is to develop an ICP for the continuing care of patients with alcohol dependency. To develop such an ICP, a systematic approach should be applied based on an internationally validated approach (14).

In this project we addressed the following specific objectives

1. to identify interventions for AUD sustaining the principles of integrated care and to evaluate their effectiveness;
2. to systematically develop evidence-based indicators to measure the quality of continuing care for AUD;
3. to assess continuing care for AUD currently provided in Belgium;
4. to identify barriers and facilitators related to current continuing care for AUD.

We defined 'continuing care' as the treatment phase following an alcohol detoxification treatment.

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Development and validation of quality indicators on aftercare for patients with AUD: a Delphi study

Running title: quality indicators on aftercare for AUD

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Abstract

Aims: To develop indicators to assess quality of aftercare for persons with AUD.

Methods: A guideline-based RAND-modified Delphi method was used to develop and validate indicators with regard to the process and outcome of aftercare. We systematically searched for evidence-based guidelines and existing quality indicators. A multidisciplinary expert panel prioritized recommendations using a written questionnaire followed by a group discussion. Important recommendations were then translated to quality indicators. The panel subsequently selected indicators that were measurable and applicable in Belgium. In a final round the indicators face-validity was assessed.

Results: We extracted 69 recommendations from 6 guidelines and 17 relevant quality indicators. Thirteen indicators remained after 3 written rounds and 2 group discussions.

Conclusions: This study describes a systematic approach to develop and validate quality indicators for aftercare for AUD. The final set of selected indicators consisted of 10 process and 3 outcome indicators. As the level of evidence of effective aftercare components is very low further development of the indicators is recommended.

Short summary

This study describes a systematic approach to develop and validate quality indicators for aftercare for AUD. The proposed set of indicators consisted of 10 process and 3 outcome indicators. As the level of evidence of effective aftercare components is very low further development of the indicators is recommended.

1. Introduction

Severe alcohol use disorder (AUD) is a progressive and chronic disease, which results from a long-lasting exposure to alcohol. Alcohol dependence affects physical, psychological and social functioning and relapse is common. Indirect societal costs of alcohol dependence are estimated to reach up to 0.64% of European countries' annual gross domestic product, illustrating the burden of alcohol dependence to society (1). Therefore, alcohol dependence should be recognized and managed adequately.

Care for AUD typically follows an acute treatment model. Such model provides detoxification and rehabilitation in specialized treatment centers for some patients. Aftercare or follow-up may be provided though not systematically. Over de decade ago, McLellan, Lewis, O'Brien & Kleber (2) acknowledged the lack of proactive efforts to ensure continuity of care. A further bottleneck is a lack of integration of care; treatment programs are provided separately and different health care settings function independently (3). According to recent insights, care for alcohol dependence should be organized from a chronic care perspective (National Institute for Health and Care excellence [NICE], (2, 4-6). Treatment in such perspective would include detoxification or initial treatment in a specialized psychiatric care setting followed by systematic and continuing aftercare, in order to sustain the achieved positive effects (6).

Some research is available on effective elements of aftercare. For example, attendance at Alcoholics Anonymous (AA) meetings after inpatient treatment is related to better outcomes (7), as well as intensive referral to AA (8). Hence, NICE (4) recommends that people with alcohol dependency should be "helped to participate in community support networks and self-help groups by encouraging them to go to meetings and arranging support so that they can attend". Our systematic review observed slightly better outcomes for continuing care interventions actively involving the patient, compared to 'usual care' (9), a trend recently confirmed (10,11).

In continuing care for patients with AUD, multiple isolated continuing care interventions have been described in a wide variety of formats and modalities (5, 6). Nevertheless, fully integrated care programs (ICP) have never been developed. The Belgian ICARUS project aims to develop such an ICP for the continuing care of patients with alcohol dependency.

In order to evaluate the effects of this ICP an accurate assessment of the quality of care is needed. Quality indicators are widely used to measure the quality of care in terms of process as well as outcomes. Because development and use of quality indicators in the European mental health care system is still in developmental stage (12), we aimed to develop and validate indicators to assess the quality of aftercare for patients with alcohol dependence.

The research question is: which outcome and process indicators can be validated to assess the quality of AUD aftercare? Process indicators relate to actions or activities that are undertaken, while outcome indicators relate to changes in health status or quality of life for individuals or populations, but may also relate to wider outcomes such as satisfaction or experience of people using services, changes in knowledge and changes in behavior (NICE, 2014). The indicators can be used to assess the quality of current aftercare and identify valuable elements of already applied interventions. Finally, the indicators could enable the assessment of an integrated care program on itself.

2. Material and methods

To develop quality indicators for aftercare, a systematic, guideline-driven approach of the RAND-modified Delphi-method in 4 steps was used. This method has been used before in primary care and results in a set of indicators that are face and content valid (13-15). Target audience for the quality indicators are adult patients who received rehabilitation in a specialized care setting for alcohol dependence. This study was conducted between May 2014 and January 2015.

2.1 Step 1: systematic search

First, we performed a systematic search to identify guidelines and existing quality measures or indicators.

2.1.1 Sources

The following electronic databases were systematically sought through using a sensitive strategy: Medline, Embase, Cinahl and PsychInfo.

In addition, we searched the following databases:

- Guidelines International Network
- The National Guideline Clearinghouse
- The New Zealand Guidelines Group
- The Scottish Intercollegiate Guidelines Network (SIGN)
- Domus Medica (Belgian Association for Flemish General Practitioners)
- Nederlands Huisartsen Genootschap (Dutch Association for General Practitioners)
- Dutch Institute of Healthcare Improvement CBO
- Société Scientifique de Médecine Générale (SSMG)
- National Institute of Clinical Excellence (NICE)
- Ebmpracticenet
- World Health Organization (WHO guidelines on mental health and substance abuse)
- Resultaten Scoren - Kenniscentrum Verslaving
- National Quality Measures Clearinghouse
- Trimbos Instituut
- CQAIMH databank

The Association for Alcohol and other Drug Problems [Vereniging voor Alcohol en andere Drugsproblemen], and the portal of the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA) provide an overview of (European) guidelines for treatment of substance misuse up to 2013 and these were also screened for relevance.

2.1.2 Search strategy

The search strategy was based on search terms for the following concepts: alcohol misuse, continuing care, guidelines or performance indicators. For each concept we used MeSh terms and free text words, and these were combined using the Boolean operator 'OR'. Search terms of the concept were combined using the Boolean operator 'AND'. The full search strategy for PubMed is available as Supplementary material (Appendix 1). This search strategy was adapted for other databases.

The screening was performed by two independent reviewers. All records were screened for relevance using the following criteria:

1. The document is an original report; and
2. Contains health care recommendations or performance indicators on continuing care; and
3. Focuses on the adult population;
4. Who received rehabilitation treatment in a specialty care setting (defined as: inpatient or intensive outpatient program of at least seven days, not just detoxification);
5. For alcohol dependence. Recommendations on continuing care for drug dependence or combined alcohol- and drug dependence were excluded.

Evidence-based guidelines are statements that include recommendations intended to optimize patient care that are informed by a systematic review of evidence and an assessment of the benefits and harms of alternative care options (16) . Therefore, we excluded guidelines that were not based on a systematic literature review or did not report the results of this process. The reason for excluding guidelines was noted. The methodology of all included guidelines was evaluated by two reviewers using the AGREE II instrument (17).

From each guideline two independent persons extracted all recommendations on aftercare for alcohol dependent persons who completed a rehabilitation treatment in a specialized center. The evidence supporting the recommendation was also retained. In total, 69 recommendations were extracted.

2.1.3 Search for additional outcome indicators

As only a few outcome indicators were expected from the sources above, we used 2 additional sources for potential outcome indicators. A first step to develop outcome indicators, as

suggested by Perlman et al. (18) is to select domains that are relevant to aftercare for AUD. For this purpose the 10 outcome domains of the Substance Abuse and Mental Health Services Administration (SAMHSA) were used (Substance Abuse and Mental Health Services Administration (19).

Second, we listed outcome measures used in (published protocols of) Cochrane systematic reviews on the treatment of patients with alcohol dependency. A specific search was performed and 7 reviews were identified (20-25). Nine unique outcomes measures were used in these reviews and these were subsequently assessed by the experts as potential relevant outcome indicators.

2.2 Step 2 - Recruitment expert panel

Subsequently, we recruited a panel of experts. Panel members had to have ample professional experience in treatment of AUD and organization of care and recognized as such by their peers independent of the study. Ten panel members, 9 from various disciplines relevant to aftercare, confirmed their cooperation. The last member was a patient with alcohol dependence who received aftercare in the past.

2.3 Step 3 - Prioritization

Then, all relevant recommendations, existing quality measures, outcome domains and measures were prioritized using a RAND-modified Delphi approach. The prioritization started with a written feedback round where experts could provide an individual rating of the recommendations. All experts were asked to rate the importance of each recommendation on a 9-p Likert scale (1=very low importance; 9=very high importance). Experts were also encouraged to propose new quality indicators on topics they perceived to be missing.

The results of this written feedback round were analyzed into a summary report. In this report all items (recommendations, indicators, outcome domains or measures) received a label according to their potential to be used as quality indicator: high, low or uncertain. Items with a median of 7, 8 or 9 were labeled high potential. Those with median scores 4, 5 and 6 were labeled uncertain. Items on which many experts did not have an opinion were also labeled uncertain. Items with median scores of 1, 2 and 3 were labeled 'low potential'. Subsequently a panel consensus meeting was organized. During this meeting the results from the written feedback round were discussed. Where needed (mainly in case of several 'no opinion' scores), further information about the item was provided. All items with the label 'high potential to be used' and all items that were judged to be important during the expert meeting were withheld. Based on this round and meeting 78 items were kept for the next round.

During the first meeting the experts suggested formulating the recommendations of the guidelines into indicators before the next round because many recommendations were perceived as unclear. Thus, for the 2nd round all recommendations were translated into one or multiple indicators. During this round 121 indicators were discussed. Experts were asked to assess the applicability on measurability of the indicators each on a 9-p Likert scale. In addition

they were asked to appreciate how important an indicator was compared to all other indicators, also on a 9-p Likert scale.

Indicators that received a median score of 7, 8 and 9 on both applicability and measurability were judged to have high potential to be used. Indicators with lower scores were judged to be of uncertain potential. A second expert meeting was organized to discuss the indicators with high and unclear potential to be useful. Based on this round and meeting, 16 potential indicators were kept for the following round.

2.4 Step 4 - Validation

In this phase the potential relevant indicators were evaluated for final approval. In a written round, experts were questioned whether the indicators can be used to assess quality of aftercare. They also were asked to judge for each indicator whether in current practice there was still room for improvement in what they measure. Indicators were considered face-valid when at least 75% of the panel members agreed that they assess quality of aftercare and that there was room for improvement.

3. Results

3.1 Systematic search

The search of electronic databases generated 1433 records. The search in other sources, mainly websites, yielded 103 potential relevant guidelines and 20 potential relevant indicators (Figure 1). Of these, 6 guidelines had recommendations on aftercare for persons with alcohol dependency (see Box) and 28 (process or outcome) indicators were judged to be relevant for aftercare. The results of the AGREE II assessment of selected guidelines are presented in Table 1.

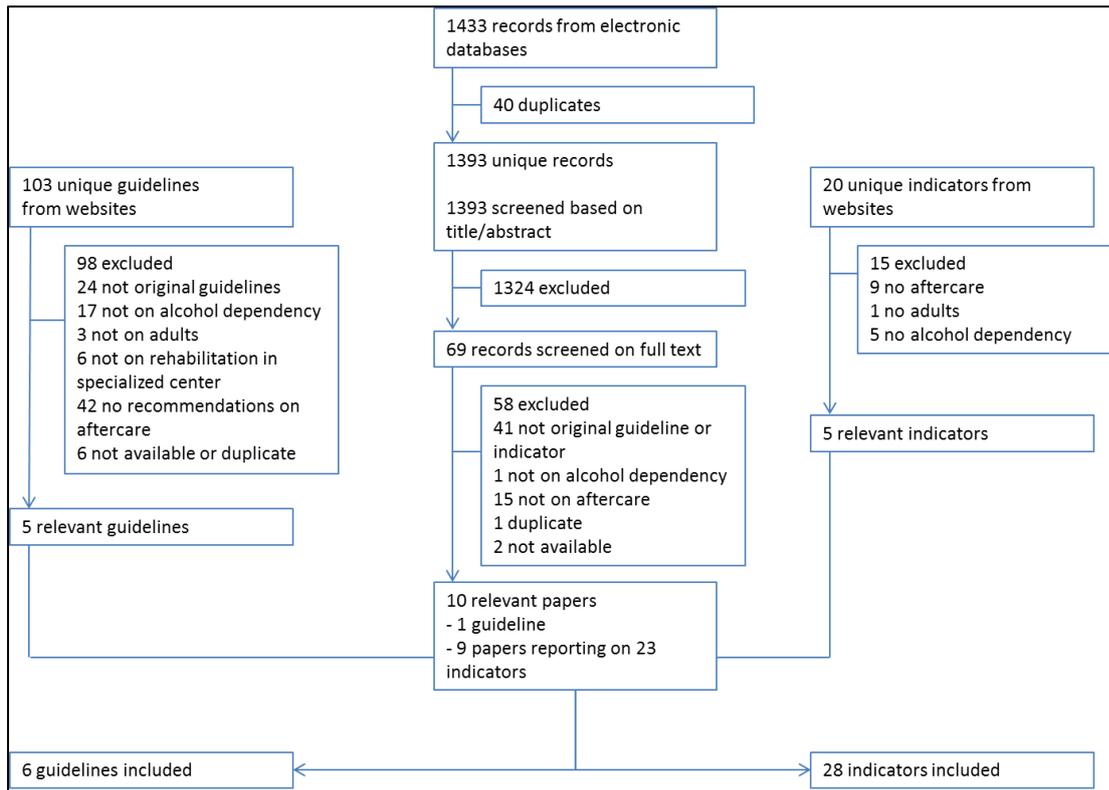


Figure 1. Chart illustrating flow of guidelines and indicators that were in- and excluded in the review

Box 1. Evidence-based guidelines with recommendations relevant for aftercare:

- Guidelines for the treatment of alcohol problems (Australia, 2009 developed by NDARC)
- Modalités de l'accompagnement du sujet alcoolodépendant après un sevrage. Conférence de consensus (France, 2001 developed by HAS)
- Post-acute treatment of alcohol abuse and dependence (Germany, 2006 developed by AWMF)
- Alcohol-use disorders: diagnosis, assessment and management of harmful drinking and alcohol dependence (UK, 2011 developed by NICE)
- VA/DoD clinical practice guideline for management of substance use disorders (US, 2009 developed by Department of Defense)
- BAP updated guidelines: Evidence-based guidelines for the pharmacological management of substance abuse, harmful use, addiction and comorbidity: Recommendations from BAP (UK, 2012 developed by BAP).

Table 1. Overview of methodological quality of selected clinical guidelines. Scores are AGREE II sum scores for each domain (% of maximal score).

Guideline ID (country and year of publication)	Target and aim	Stakeholder involvement	Rigour of development	Clearness	Applicability	Editorial independence
Australia 2009	74	69	60	71	25	14
France 2001	86	62	31	69	30	54
Germany 2006	55	36	34	48	14	21
UK 2011	95	95	78	76	32	57
US 2009	95	60	56	86	46	14
UK 2012	83	79	51	69	25	39

3.2 Delphi process

The first written questionnaire consisted of 69 recommendations, 17 indicators, 11 outcome domains and 8 outcome measures. Eight experts completed the questionnaire. Based on the results of the written round and the expert discussion meeting, 27 items were considered not relevant for the quality of aftercare and consequently excluded. The second written questionnaire consisted of 110 indicators. Of these 81 were discarded at this phase; 63 were considered not measurable in practice and 18 not applicable in Belgium (available online). Another 13 were excluded after expert discussion. Eight experts completed the second questionnaire. The third written questionnaire evaluated 16 potential relevant, measurable and applicable indicators. Three were considered not to be valid or without room for improvement and therefore excluded. Nine experts completed this questionnaire.

The final set of validated indicators consists of 13 indicators (Table 2). Of these, 10 relate to the process and 3 relate to the outcome of aftercare.

Table 2: The set of validated indicators on aftercare

1. The proportion of patients that was informed on a self-help group for alcohol misuse.
2. The proportion of patients for whom psychosocial relapse prevention strategies are used.
3. Within the group of patients that agreed to involve the environment in continuing care, the proportion of patients for which the environment is actually involved.
4. Within the group of patients that received medication, the proportion of patients that also receives psychosocial interventions.
5. The proportion of patients that during the process of detoxification is informed about the importance of long-lasting involvement in treatment.
6. The proportion of patients that is followed at least 3 months after their discharge.
7. Within the group of patients that opted for moderation, the proportion of patients for whom harm reduction strategies are used.
8. The proportion patients for whom the continuing care plan is developed in consultation with the patient.
9. The proportion of patients that received any professional or non-professional continuing care within 14 days after discharge.
10. The proportion of patients that is satisfied with the quality of contact with his care giver(s).
11. The proportion of patients that is abstinent at three* months after discharge.
12. The proportion of patients that functions well at three* months after discharge.
13. The proportion of patients that feels well mentally at three* months after discharge.

* also other time periods, including longer follow-up should be considered

Three indicators were not kept in the final round. These were:

1. The proportion of patients for which a personal counselor has been identified. This was not selected because 30% of experts judged that within current practice there was no room for improvement on this issue. This means that the majority did think this was a reasonable indicator.
2. The proportion of patients that is informed on medication for alcohol addiction. This was not selected because 35% judged that this was not a valid indicator and 45% judged that there was no room for improvement. Some experts argued that medication is part of the treatment which is less relevant for aftercare.
3. The proportion of patients with a (paid part-time or fulltime) job or education at three months. 35% judged this to be not a valid indicator. Arguments were that experts thought this was not realistic for the majority of patients. Also there was uncertainty about the subgroup of patients that are not able to work and how to define this population.

4. Discussion

This study proposes a set of indicators to measure the quality of aftercare of patients who have been treated for AUD in a specialized setting. The indicators are built on international evidence-based guidelines on alcohol dependence and existing quality indicators and these were discussed and fine-tuned by a multidisciplinary expert panel. Although the expert panel was national, we are convinced these results are of global interest. First, the indicators are built on international guidelines. Second, selection was mainly based on methodological criteria which are valid everywhere. Furthermore, the national context was only taken into account during the last step. We added a table with the indicators that were excluded due to lack of applicability in Belgium, these could be reconsidered by other countries wishing to apply our results in their own regional context.

AUD is increasingly considered to be a chronic health problem, presenting similarities with many other chronic diseases in heritability, course and response to treatment (2). Therefore, a call is made to organize the care for patients with AUD from a chronic care perspective (2, 6). Wagner introduced the Chronic Care Model to optimize the care for patients with a chronic disease. His model relies on the concept of continuous, integrated care and stimulates the interaction of informed, activated patients with prepared, proactive practice teams (26). In various chronic diseases like depression, COPD and diabetes, Wagner's model has proven to be effective (27). The selected indicators fit well in the concept of Wagner's model, in particular because the indicators clearly underline the importance of patient centeredness and continuity of care.

The proposed set consists of 13 indicators, 10 refer to process of care and 3 to outcome of care. The indicators on process of care refer typically to psychosocial actions of health care workers in which the patient plays a central role. Examples are: informing patients on self-help, providing psychosocial interventions, and keeping patients involved in the treatment. This fits

the current perspective of patient-centered care. The bottom-line of such care is that the care is organized around the patient in such way that all needs and preferences are met (28). Patient-centered care is identified to be one of the factors that constitute high-quality health care (29). Patient centered care leads to higher patient engagement which in turn seems to be associated with better perceived health outcomes (30).

Our set of indicators differs from any of the existing (sets of) quality indicators on treatment for AUD, although none applied specifically on aftercare. Common existing quality indicators for mental health care refer to the number of contacts, and services, the continuity of these contacts and the prescription of medication. Most of the existing sets of indicators are based on current databases or administrative data. Examples are the Washington Circle performance measures (31) or the international measures of quality of care for mental health care (14). Advantage of such indicators is that it is easier to collect data on a large scale. Downside is that measures of rate-based processes cover only some aspects of quality of aftercare. Potential relevant aspects of quality of aftercare that are missing are patient satisfaction, clinical outcomes and evaluation of the extent to which the evidence-based interventions are implemented correctly (14) and these are included in our set of indicators.

In contrast to other indicators in mental health, our set of indicators is guideline-driven, meaning that existing guidelines are the foundation of our indicators. Strength of such method is that guideline-driven indicators are more likely to relate to process quality, as clinical guidelines aim to improve quality of care (32). This is also a rather efficient way to develop indicators, considering the use of an existing overview of the evidence.

Evidence underpinning the recommendations that were selected for indicators was typically low or sometimes indirect. For example, the indicator “the proportion of patients that was informed on a self-help group for alcohol misuse” was based on the recommendation ‘Assertive referral practices to Alcoholics Anonymous increase participation and improve outcome (33), which received level of evidence I, representing evidence from large representative population samples. However, the evidence that participation in self-help groups is associated with improved outcomes is observational. Concretely, the evidence suggests that patients who attend more sessions have better outcomes compared to those who attend fewer AA sessions. However studies have methodological shortcomings, such as a large number of drop-outs and no comparison group.

Strength and limitations

This study was based on a multidisciplinary panel of experts. The response rate for the online questionnaire was high, but the involvement in group discussion was moderate. Although experts who could not be present at the meeting were asked to provide written comments on the notes of the meeting, this option was used scarcely. This may have affected the final results of our study.

A strength was the incorporation of patient views. A study on guideline-based indicator development of den Breejen, Nelen, Schol, Kremer & Hermens (34) showed that patients’ panel select different indicators compared to a panel that consists of professionals. From a set of 119 potential indicators, the patient’s panel selected 16 and the professionals’ panel selected 18. Only 5 indicators were selected by the patient’s panel as well as the professional’s panel. Our

final set includes one indicator that was based on solely input of the patient, which is “the proportion of patients that is satisfied about the quality of contact with his care giver”. The patient stressed that a trustful relationship with the professionals was crucial for the quality of aftercare.

Although the selected guidelines had to be based on systematic review of evidence, all recommendations on aftercare were typically based on expert consensus. This illustrates a weakness of evidence on aftercare; little high quality studies are available. This was also an important finding of our systematic review of effectiveness of aftercare (9). This has implications for the validity of our set of indicators. Currently, we cannot propose a wide-spread implementation of these indicators. Pre-requisite for this would be a better evidence-base. A next step in our research is the development of an integrated care program for aftercare that could be evaluated using these indicators. Then, this program should be evaluated. Based on such study, these indicators can be refined where necessary. Our research team plans a pilot study on this topic.

The selected set of indicators has a high potential to determine the quality of care. However, problems may arise with regard to their measurability. First, the systematic registration of indicators in the medical file is currently not a standard practice. It will require a strong commitment from the involved caregivers. Second, multiple caregivers are involved in aftercare for patients with AUD: psychiatrist, psychologist, general practitioner, social worker, etc. All of them use their own patient files. The investigators will have to extract data about the indicators from these different files, and most probably also needs to interview the patient. This will obviously be time-consuming. A possible solution lays in the development of a shared medical file, online, which can be used by all caregivers but where also the patient has partly access. Hermann et al. (14) already noted that current indicators data on medical interventions are easier to capture than data on psychosocial interventions. This observation remains valid today.

Implications for practice

A recent study on how alcohol dependent patients experience the alcohol treatment system suggests that the current care pathway for alcoholics expects too much of the patient (35). Typical problems noted by patients were: they had to attend numerous appointments, had often infrequent contact with services and engagement with multiple workers and agencies in order to obtain treatment. Gilbert et al. argue that such requirements do not fit with characteristics of alcohol dependence including disorganization, decreased ability to make judgments, cognitive impairment and fluctuating motivation. The authors conclude that pathways should reflect the capacity and capabilities of patients to be successful in supporting recovery. With respect to our selected indicators, this would mean that all indicators need to be implemented from the patients’ point of view. For example, when informing a patient of self-help groups this would not mean providing the patient with a leaflet, but instead informing a patient on individual basis. For some this may mean also making appointments and introducing the self-help groups to the patient or even assist the patient in arranging transportation to the meetings.

5. Conclusions

This study describes a systematic approach to develop and validate quality indicators for aftercare for alcohol dependence. The final set of selected indicators consisted of 10 process

and 3 outcome indicators. As the level of evidence of effective aftercare components is very low, further development of the indicators is recommended.

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