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Patient-centeredness of integrated care programs for people with multimorbidity. Results from the European ICARE4EU project

IRIS VAN DER HEIDE^{1,2}, SANNE SNOEIJIS¹, SABRINA QUATTRINI³, VERENA STRUCKMANN⁴, ANNELI HUJALA⁵, FRANÇOIS SCHELLEVIS^{1,6}, MIEKE RIJKEN¹

¹ Netherlands Institute for Health Services Research (NIVEL), Utrecht, The Netherlands

² Faculty of Medicine, Respiratory Medicine Division, University of British Columbia, Vancouver, Canada

³ Centre for Socio-Economic Research on Ageing, National Institute of Health and Science on Ageing (INRCA), Ancona, Italy

⁴ Technical University of Berlin, Berlin, Germany

⁵ University of Eastern Finland, Kuopio, Finland

⁶ VU University, Amsterdam, The Netherlands

HIGHLIGHTS

- In many European countries integrated care programs exist that aim to improve care for people with multimorbidity.
- These programs provide examples of how patient-centeredness could be improved at practice level.
- To improve patient-centeredness, it is important to make adaptations to the care delivery process.
- Evaluation of integrated care programs is needed to support policy development and the implementation of good practices.

ABSTRACT

Introduction

This paper aims to support the implementation of patient-centered care for people with multimorbidity in Europe, by providing insight into ways in which patient-centeredness is currently shaped in integrated care programs for people with multimorbidity in European countries.

Methods

In 2014, expert organizations in 31 European countries identified 200 integrated care practices ('programs') in 25 countries of which 123 were included in our study. Managers of 112 programs from 24 countries completed a questionnaire

about characteristics and results of the program, including questions on elements of patient-centeredness. Eight programs that were considered especially innovative or promising were analyzed in depth.

Results

Programs used various methodologies to involve people with multimorbidity in decision-making, such as motivational interviewing and narrative counseling techniques. In 79 programs individual care plans were developed together with patients. Few programs had already been systematically evaluated, but in one program it was shown that working with individual care plans based on patients' goals and resources resulted in increased patient satisfaction with care. Various barriers to deliver patient-centered care were reported, including inadequate knowledge and skills of both patients and professionals.

Conclusion

In many European countries innovative approaches are applied to increase patient-centeredness of care for people with multimorbidity. To assess their potential benefits and conditions for implementation, thorough process and outcome evaluations of programs are urgently needed.

1. INTRODUCTION

An estimated 50 million people in Europe suffer from multiple chronic conditions (multimorbidity), a number that is expected to increase [1]. People with multimorbidity usually need long-term care from professionals of multiple disciplines. In health systems all over Europe, care is currently organized around single diseases and treatment decisions are often directed exclusively at improving clinical outcomes [2]. This care approach does not respond to the needs of people who suffer from multimorbidity. First, because evidence that disease-specific treatment options are effective in people with multiple chronic diseases is often lacking [3,4]. Clinical practice guidelines that focus on the management of a single disease can therefore be impractical, irrelevant or even harmful for people with multimorbidity [5]. Second, clinical outcomes may not always be relevant from a patient perspective, and in multimorbidity in particular, people may attach greater value to functional outcomes and wellbeing.

Health systems could become more responsive to the comprehensive needs and preferences of people with multimorbidity, when a shift is made from a disease orientated to a person-centered care approach [6]. Person-centered or patient-centered care encompasses many facets and can be defined in various ways [7], but in essence it refers to "care that is respectful of and responsive to individual patients' preferences, needs, and values, and ensures that patient values guide all clinical decisions" [8]. For people with multimorbidity, some aspects of patient-centered care seem especially important in order to experience good quality of care: 1) taking their individual needs, preferences and resources as a starting point for the development and evaluation of an individual care plan [9]; 2) involving informal carers in the care process [10,11]; and 3) involving all relevant professional disciplines in the care process and making sure that the delivery of multidisciplinary care is coordinated [10].

Individual care plans are intended to support the provision of holistic care that is tailored to the needs and preferences of patients [12,13]. Therefore, individual care plans need to include the health goals that are considered relevant by patients. These health goals reflect patients' needs and priorities and should guide the process of shared decision-making. For this purpose, patients need to be well-informed about the care and treatment options they have in all phases of their illness process to meet their (changing) needs, and their preferences with respect to these options should guide all care and treatment decisions [5,7]. In addition, to customize care to the needs of patients, it is important to take patients' resources into account [14,15]. Patients' resources may include their self-efficacy expectations, health literacy level and social network [16–18], next to socio-economic resources such as income or insurance plan. Patients with strong self-efficacy beliefs, a high level of health literacy and a strong social network may be more capable of managing their health condition and coordinating care than patients with less of these resources [16–18]. This latter group of patients may need more support from care professionals in managing their health and care situation.

Many patients with multimorbidity receive support from informal carers (family members or friends), who should therefore be recognized as co-care providers [10]. However, the burden of caring may be high, both physical and emotional, and could even lead to health problems of informal carers [19]. Therefore, informal carers should also be regarded as co-clients, with specific needs for support. This double role of informal carers need to be taken into account by professional care providers when providing care to people with multimorbidity.

Receiving care from different care providers is often necessary, but could at the same time be burdensome for people with multimorbidity. People with multimorbidity may, for instance, need to follow various treatment regimens and frequently visit multiple care providers [20]. Receiving uncoordinated care from multiple care providers could lead to inefficient care and unnecessary duplications, for instance of diagnostic tests [3]. In some cases a lack of coordination could even induce health risks for patients, for instance when patients receive conflicting treatment and medication recommendations from different care providers [20]. Multidisciplinary collaboration and coordination of care is therefore of great importance for people with multimorbidity. Coordination of care does not only concern interdisciplinary coordination, but also continuity of care over time, for instance through information sharing and the establishment of long-term collaborations [21].

Various key papers and reports have been published on the topic of patient-centeredness [22–29]. Yet, there is hardly any evidence on how to provide patient-centered care specifically to people with multimorbidity, because few scientific studies have been conducted in this area [30]. Therefore, in this study we aim to gain insight in approaches to improve patient-centeredness in multimorbidity care by drawing on practice experiences. The objectives of this paper are to provide insights in 1) the extent to which, and 2) ways in which patient-centeredness is currently addressed in integrated care practices or 'programs' for people with multimorbidity in European countries. These insights will be obtained from data collected in the ICARE4EU project, which received co-funding from the EU Health Programme 2008–2013 [31]. The aim of the ICARE4EU project, which ran from 2013 to 2016, was to increase and disseminate knowledge of European integrated care programs addressing multimorbidity, and to identify high potential programs from the

perspectives of their patient-centeredness; management practices and professional competencies; the use of eHealth technologies; and their financing methods. Insights from the current paper on the ways patient-centeredness is addressed in these programs could be used by policy-makers and service providers to develop policies, strategies and practices aimed at providing patient-centered care for people with multimorbidity.

2. METHODS

2.1. Identification and selection of programs

In 2014 the ICARE4EU project [31] started with the collection of data about local practices or ‘programs’ that provide integrated care for people with multimorbidity. This was done with the help of expert organizations in 31 European countries. These expert organizations were selected from the international network of the ICARE4EU partner institutes, which included governmental bodies and knowledge institutes in the 31 countries. Expert organizations had to meet the following criteria: 1) be a formal body; 2) have expertise on chronic illness care, preferably also on multimorbidity care; 3) have a nationwide overview of developments in (national, regional or local) chronic illness care and/or long-term care in the country (innovative, multi-disciplinary care approaches) or have access to this information by an extensive network of experts/expert organizations throughout the country; 4) be able to communicate with the project team in English; 5) be able to provide reliable information on the multi-disciplinary care approaches/programs for people with multiple chronic conditions in their country; and 6) have no competing interests (for instance, financial interests in promotion of specific programs). The eligibility of potential expert organizations was checked by the ICARE4EU project team following a stepwise procedure, including at least two interviews by phone. Expert organizations that were considered eligible and agreed to participate were subcontracted by the ICARE4EU partner institutes and received detailed information and a list of criteria, defined by the ICARE4EU project team, that all had to be met by the programs in order to be included. These criteria were:

- being designed to provide care for (adult) people with multimorbidity or contain specific elements to provide care for people with multimorbidity,
- target people with multimorbidity, defined as two or more medically (i.e. somatic and/or psychiatric) diagnosed chronic (not fully curable) or long lasting (at least six months) diseases, of which at least one of a (primarily) somatic nature,
- involve one or more medical service(s), and involve cooperation between at least two services (these services may be part of the same organization, for example services within a hospital, or may be part of different organizations, for example between medical care and social care),
- being evaluated or evaluable in some way,
- currently running (in the year of the field study) or finished less than 24 months ago or starting within the next 12 months.

A total of 200 programs from 25 countries were initially identified by the expert organizations. After being carefully reviewed by the ICARE4EU project team, 123 programs from 25 countries met all criteria mentioned above and were therefore eligible.

2.2. Data collection

In 2014, when the data was collected, questionnaires covering our research themes were neither available in the many languages spoken in the EU nor validated in all countries. Therefore, new survey questions were developed by the ICARE4EU project partners, which was done by a stepwise approach, in which the research themes (e.g. person-centeredness, integrated care, financing) were first identified by all project partners together, then operationalized based on theoretical models and empirical studies by the project partner with expert knowledge of the particular theme, and subsequently formulated in survey questions, which were commented upon by all project partners. The (adapted) survey questions were then pretested by the ICARE4EU project partners in their own country, and translated in eleven languages by applying forward translation only.

The expert organizations were asked to send information about the ICARE4EU project and a link to the survey questions to the program managers of all eligible programs they had identified in their country. The survey questions covered a broad variety of program characteristics, including characteristics related to patient-centeredness. In this way data were received from 112 programs in 24 countries, as the data collection of the 11 programs identified in France failed, due to staff problems of the French expert organization. For detailed information on the characteristics of these 112 programs, please see [32,33].

The next step in the ICARE4EU project was to select programs from the list of 112 programs for further study by evaluating the survey data. To be selected, programs had to meet the following criteria:

- being implemented,
- having included a substantial number of patients,
- being evaluated or planned to be evaluated.

In addition, programs had to show innovative or interesting elements from one or more of the four perspectives of the ICARE4EU project [31]: 1) patient-centeredness, 2) integration of care, 3) use of e-health technologies, and 4) financing methods. This was evaluated based on quantitative data (e.g. reported program characteristics). Based on these criteria, all project partners provided each program with a score, resulting in a short list of 25 programs with potential for further study. From this short list the project partners selected two programs for each perspective, that were considered specifically innovative or interesting from this perspective. This selection was made based on the qualitative descriptions of the aims of the program, its strengths and weaknesses, and uploaded policy or evaluation reports (if any). The project team reached consensus on the selection of the following eight programs for further study: PROTOCOL 3 Program (Belgium) [34], 'Diabetic care' NPO (Bulgaria) [35], TeleRehabilitation program (Cyprus) [36], POTKU project (Finland) [37], Gesundes Kinzigtal program (Germany) [38], INCA model (the Netherlands) [39], Clinic for Multimorbidity and Strategy for Chronic Care in Valencia Region (Spain) [40], and Poypharmacy (Denmark) [41]. Subsequently it was checked with the country experts in the respective country whether it was indeed an innovative or interesting program (as a 'second opinion') and in some cases information was also verified by contacting the program manager. See Fig. 1 for a flow chart of the program selection process.

[FIGURE 1]

All selected programs agreed to be visited by ICARE4EU project team members, and semi-structured interviews with different stakeholders (program manager, care professionals from various disciplines or services, representatives of patients' or informal carers' associations) were done, in addition to the analysis of (translated) program materials or reports. The interviews were conducted by two ICARE4EU project team members from different partner organizations, by the use of a topic guide. In addition to the listed topics stakeholders were free to discuss other relevant program related topics. Observation notes were taken during this interview and based on these notes a short report was made by the two team members who conducted the interview. During program visits, an interpreter was present when needed to assure smooth communication. See Appendix A in Supplementary materials for more details regarding the site visits.

In the current paper information from these site visits is used in addition to the survey data based on the 112 programs, in order to increase our understanding of how programs have incorporated elements of patient-centeredness in their care delivery to people with multimorbidity and to illustrate the results from the survey.

2.3. MEASURES

2.3.1. Patient-centeredness

Based on literature [42–51], we distinguished the following elements of patient-centered care: 1) taking patients' needs, preferences and resources into account in developing and implementing an individual care plan, 2) involving informal carers as co-clients and co-care providers, and 3) multidisciplinary collaboration and care coordination.

With respect to the first element, we developed survey questions to assess whether programs: a) addressed specific subgroups (people aged >65; people with low health literacy; people from low income groups; ethnic minorities; people with learning/mental disabilities; people with cognitive impairments; people with sensory impairments; people with (other) physical disabilities; people living in socially deprived areas; other subgroup); b) provided patient education materials (yes/no) and if so, whether these materials were adapted for specific patient characteristics (level of health literacy; language; culture; other); c) applied methodologies or tools to involve patients in decision-making (motivational interviewing; providing informational leaflets with treatment options; using web based tool to prepare patients for consultations; active participation of patients in the decision making process concerning care choices; active participation of patients in the development of a personal care plan; asking an informal carer to attend the consultation; other); d) developed individual care plans together with all or part of the participating patients (yes/no).

To assess the involvement of informal carers, we formulated three survey questions: a) whether informal carers were a target population of the program (yes/no); b) whether informal carers were addressed in the program as co-clients (yes/no); c) whether informal carers were involved in the program as co-care providers (yes/no). Regarding collaboration and coordination, we formulated survey questions about: a) whether improving coordination of care and/or multidisciplinary collaboration and/or integration of units (within one organization) and/or integration of care organizations

were main objectives of the program (yes/no); b) whether a single care provider was responsible for general communication with the patient (yes/no); c) whether multi-professional care groups had been established (yes/no); d) whether a digital communication system was used to support communication between care providers (yes/no).

2.3.2. Barriers for patient-centered care

To assess potential barriers to improve patient-centeredness, we asked the respondents of the survey questionnaire to indicate to which extent they agreed or disagreed that the following issues [52] were hampering patient involvement or a patient centered approach in the program: inadequate knowledge or skills of care providers; inadequate knowledge or skills of patients; negative attitudes of care providers; negative attitudes of patients; inadequate support for care providers (e.g. education, tools); inadequate support for patients (e.g. education, tools); inadequate collaboration between care providers; lack of time of care providers; lack of a clear managerial vision or strategy on patient involvement/patient centeredness; inadequate funding (e.g. for implementation of supportive tools); inadequate support for informal carers as co-care providers.

2.4. ANALYSIS

The survey data were analyzed descriptively (e.g. frequencies) by IvdH and illustrated by qualitative information obtained from the short reports based on the notes taken during the eight site visits. In the results section, information based on the site visits will be presented in text boxes.

3. RESULTS

3.1. Patient involvement in designing the programs

Although the focus of this study is on the extent and ways key aspects of patient-centeredness are addressed at the individual (micro) level in integrated care programs targeting people with multimorbidity, we first describe here to what extent patients and/or informal carers were involved at a collective level in the development and design of the programs. Data provided by the program managers show that patients or their representatives were involved in the development of 60 of the 112 programs (54%). Their level of involvement, in terms of levels of a participation ladder [53], in most of these programs was however relatively low. In the majority of these programs patients or their representatives were informed (38 programs) and/or consulted (42 programs) about the development of the program. More advanced levels of patient involvement were reported for less programs: in 22 programs (representatives of) patients were asked for their advice, which was in principle binding, in 26 programs patients worked in partnership with professionals to develop the program ('co-producing') and in five programs patients had a final vote in decision-making about the development of the program. Few programs had been (co-)initiated by organizations of patients (10 programs) or informal carers (2 programs). Despite the relatively low level of patient involvement at the collective level, most programs aimed to improve patient involvement or the involvement of informal carers at the individual level, respectively in 82 and 52 programs these were reported as part of their main objectives.

3.2. Aspects of patient-centered care addressed in the programs

3.2.1. Responding to patients' needs, preferences and resources in developing individual care plans

As shown in Table 1, 56 of the 112 programs addressed one or more specific subgroup(s). (Frail) elderly were most often addressed as a subgroup in these programs (in 46 programs) and ethnic minorities were least often addressed (in 10 programs). Other subgroups that were addressed included people with lower health literacy, mental disabilities, cognitive impairments, sensory impairments, and people living in socially deprived areas or from low income groups.

In 69 out of the 112 programs, patient education material was provided, but only few programs had adapted their patient education materials to specific patient characteristics such as level of health literacy, other languages or cultural background.

Apart from patient education, several methodologies were used to support patient involvement in decision-making: organizing pre-treatment discussion sessions with involved doctors on how to motivate patients in decision-making; providing communication training to care providers to encourage patients to participate in decision-making; using narrative counseling techniques in order to understand the needs of patients; using web-based tools to prepare patients for their consultations; and using motivational interviewing techniques.

In 79 programs individual care plans were developed together with patients. The visited Finnish POTKU project illustrates this, as described in Text Box 1. This program, as well as a visited program from the Valencia region, also illustrates how individual care plans could take patients' resources into account, see Text Box 1.

[Box 1]

Illustration of how individual care plans could take patients' resources into account In the visited Strategy for Chronic Care in the Valencia Region special attention was paid to the care processes of highly complex chronic patients, including patients with multimorbidity. In the Strategy for Chronic Care patients' own resources to manage their condition were assessed as an important element of identifying complex patients in need for case management [40]. In this program nurses in hospitals and communities identified the most complex patients and started a joint case management trajectory with these patients. In these cases complexity referred to medical complexity and/or functional dependency, but also to fragile family support or a need for social services.

In the visited Finnish POTKU project, which main aim was to improve patient-centeredness of chronic illness in primary care, more than 16,000 individual care plans were developed. These plans consisted of five sections: 1. patient needs (which health related problems matter most to the patient?), 2. patient goals (what change in health status the patient is aiming for?) 3. measures (which health services and patient actions are planned to achieve the goals?), 4. follow-up and assessment (when and how will the implementation of the care plan and its results be evaluated?), 5. Information about prescribed medication, medical diagnoses and contact person. The POTKU project showed that the use of these individual care plans increased patient satisfaction with care: patients who had an individual care plan reported significantly higher scores on all dimensions of the PACIC (Patient Assessment of Chronic Illness

Questionnaire; [54]) than patients without such a plan [37]. In addition, care was customized according to patient profiles that were based on both the complexity of the medical condition and treatment, and on the resources patients have at their disposal to cope with their condition and care [37]. Combining these dimensions resulted in four clientships: 1. self-management clientship (medical problem not complex and good resources) 2. cooperation clientship (medical problem complex but good resources) 3. community clientship (medical problem not complex and poor resources) 4. network clientship (medical problem complex and poor resources). Identifying the clientship profile of patients guided their (multidisciplinary) care trajectories and options for self-management.

3.2.2. Involving informal carers

In 46 programs it was reported that informal carers were a target group of the care program. Informal carers were specifically addressed as co-clients in 22 programs. An example of such an approach was found in the visited Belgian SOM+ project (“Tailored Cooperation Results in a ‘plus’”), a subprogram of the PROTOCOL 3 program, see Text Box 2 for further details [34]. In 30 programs informal carers were involved as co-care providers, which implies that they were explicitly recognized as part of the team of care providers around a patient. These informal carers could, for instance, have direct contact with professionals to clarify daily care issues, as illustrated by the care model for complex patients in the Valencia Region, see Text Box 1 [40]. Next to specifically acknowledging informal carers as co-care providers and/or cooperating with them on a formal basis, informal carers were considered supporters of patients’ self-management in 63 programs. This is illustrated by the visited SOM+ project as described in Text Box 2.

[Box 2]

3.2.3. Coordination of care and multidisciplinary collaboration

In 80 programs improving coordination of care was one of the main objectives. To coordinate care three different roles of a care provider could be distinguished. First, the role of the ‘trusted doctor’, as implemented in the visited *Gesundes Kinzigtal* program, see Text Box 3 [38]. In 73 programs for each patient one specific care provider was appointed to take care of the communication with the patient. Second, a care coordinator is needed to make sure that care from different care providers does not overlap or leave gaps. In countries with a strong primary care system this role may be fulfilled by a general practitioner or practice nurse. In countries with a different health system, other care providers could take this role. In the visited Bulgarian regional NPO “Diabetic care” this coordinating role is for instance fulfilled by volunteers [35]. A third role is the role of case manager. Case management is mainly offered to complex patients, as for example in the program of the Valencia Region, see Text Box 1 [40].

[Box 3]

In 88 out of the 112 programs improving multidisciplinary collaboration was one of the main objectives. Furthermore, in 77 programs multi-professional care groups were established. However, these multi-professional care groups were most often established within one organization and did not involve professionals from other

organizations. In only few programs professionals from both health and social services were involved, whereas people with multimorbidity often need care from both sectors. Merging of different units within organizations and merging of different organizations were the least frequently reported types of collaboration, respectively in 21 and 25 programs.

In 44 programs a digital communication system was used to support communication between care providers, such as video conferences with care providers to exchange information. In two programs shared electronic health records (shared EHRs) were implemented, as part of the Strategy for Chronic Care of the Valencia Region and of the German *Gesundes Kinzigtal* program. Both programs were visited and the latter is described in Text Box 3.

3.3. Barriers to provide patient-centered care

A number of barriers to adopt a more patient-centered approach was reported in the survey (see Fig. 2). Barriers were perceived on the side of the patients, but also on the side of the care professionals and at the organizational level. For instance, inadequate knowledge and skills of patients was reported as a barrier, but also inadequate knowledge and skills of care professionals. At the organizational level, a lack of managerial vision and a lack of time, for instance due to inflexibility of the care delivery system, were reported as barriers. These findings illustrate that to improve patient-centeredness, barriers at several levels of the care system need to be addressed.

[FIGURE 2]

4. DISCUSSION

This paper provides insight in the extent to and ways in which patient-centered care is currently shaped in integrated care programs for people with multimorbidity in European countries. We found that programs use various methodologies and tools to involve people with multimorbidity in decision-making concerning their care or treatment, and that programs often develop individual care plans together with these patients and/or their informal carers. Furthermore, inspiring examples exist on how informal carers could be involved, both as co-clients and co-care providers in the care for people with multimorbidity. Besides positive developments, our findings also imply that there is still room for improvement when it comes to providing patient-centered care to people with multimorbidity. The 112 programs that we included in this study could be considered forerunners. Yet, during the development of most programs patients themselves or their representatives were not involved or only to a limited extent; having multimorbid patients or their informal carers involved as co-designers of the care program is still rare. Furthermore, informal carers were not explicitly involved as co-clients or co-care providers in most programs. In addition multidisciplinary collaboration seems still difficult to achieve. Previous research on the implementation of integrated care shows how complex it is to achieve [55,56]. Theory on implementing changes in care organizations learns that it takes a lot of time before changes are actually adopted and that different phases need to be passed [57]. The findings of this study indicate that we are currently in the phase where there is awareness of the problem, in some countries/regions more than in others, and first initiatives to change the organization and delivery of care are

being developed. This means we are still at the very beginning of this transformation process.

The findings also provide insight into barriers for the provision of patient-centered care. Inadequate knowledge and skills of patients was most often perceived as a barrier. This implies that patient empowerment and education needs (more) attention when implementing patient-centered care for multimorbidity patients, for instance by putting (more) effort in informing patients and supporting their self-management skills. Furthermore, lack of time and funding are considered important barriers, which should be taken into account when developing policies to enhance patient-centered care. It is not sufficient to have care providers that are willing to make a change; the care delivery process needs to be adapted by moving away from 'one size fits all' care to care that is tailored to the needs of patients, both with respect to the frequency, the content and the type of patient-care provider contacts (for instance, some patients might prefer e-consultations instead of face-to-face consultations). It is important to address the fact that these barriers were mostly listed by program managers and not by involved care providers. Care providers might be more likely to list the lack of managerial vision and support as a barrier.

Furthermore, patients might mention even different barriers than the ones that were identified in this study.

The ICARE4EU project contains some limitations that might have limited the insights that we obtained. In the first place, not all programs could be visited. Therefore, insight into how patient-centered care is given shape in practice was limited, since for most programs we had to rely exclusively on survey data. Nevertheless, the eight site visits substantially increased our understanding in how the health and social care system(s) and other aspects of the local context impact on the development of patient-centered multimorbidity care at the local level. Second, most programs had not been evaluated systematically (yet), which makes it difficult to draw any inferences with respect to their successfulness in improving patient-centeredness. Third, for the identification of relevant programs in European countries we had to rely on country experts. For some countries it was difficult to find a country expert organization, although eventually we were able to find one in all countries. Country experts did not always have a complete overview of all initiatives in their countries, especially in countries with decentralized health systems. Fourth, the insights as described in this paper are based on the responses of program managers. Experiences of healthcare providers and patients might have provided different insights.

5. CONCLUSION

Although inspiring integrated care practices in European countries exist that all address some aspects of patient-centeredness in the way they provide care to people with multimorbidity, there is room for improvement. Future integrated care programs that target people with multimorbidity need to support patient involvement in the development of individual care plans, tailor care to the needs of specific patient groups, explicitly involve informal carers as both co-clients and co-care providers, and establish multidisciplinary collaborations, ideally across sectors. Another recommendation is to invest in systematic evaluations of integrated care services for people with multimorbidity, in order to support policy development and further implementation of good practices.

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TABLES AND FIGURES AND BOXES

Text box 1. Illustration of how individual care plans could take patients' resources into account

In the visited Strategy for Chronic Care in the Valencia Region special attention was paid to the care processes of highly complex chronic patients, including patients with multimorbidity. In the Strategy for Chronic Care patients' own resources to manage their condition were assessed as an important element of identifying complex patients in need for case management [40]. In this program nurses in hospitals and communities identified the most complex patients and started a joint case management trajectory with these patients. In these cases complexity referred to medical complexity and/or functional dependency, but also to fragile family support or a need for social services.

In the visited Finnish POTKU project, which main aim was to improve patient-centeredness of chronic illness in primary care, more than 16,000 individual care plans were developed. These plans consisted of five sections: 1. patient needs (which health related problems matter most to the patient?), 2. patient goals (what change in health status the patient is aiming for?) 3. measures (which health services and patient actions are planned to achieve the goals?), 4. follow-up and assessment (when and how will the implementation of the care plan and its results be evaluated?), 5. Information about prescribed medication, medical diagnoses and contact person. The POTKU project showed that the use of these individual care plans increased patient satisfaction with care: patients who had an individual care plan reported significantly higher scores on all dimensions of the PACIC (Patient Assessment of Chronic Illness Questionnaire; [54]) than patients without such a plan [37]. In addition, care was customized according to patient profiles that were based on both the complexity of the medical condition and treatment, and on the resources patients have at their disposal to cope with their condition and care [37]. Combining these dimensions resulted in four clientships: 1. self-management clientship (medical problem not complex and good resources) 2. cooperation clientship (medical problem complex but good resources) 3. community clientship (medical problem not complex and poor resources) 4. network clientship (medical problem complex and poor resources). Identifying the clientship profile of patients guided their (multidisciplinary) care trajectories and options for self-management.

Text box 2. Illustration of how to involve informal carers

The visited SOM+ project (“Tailored Cooperation Results in a ‘plus’”) aimed to search for and develop new alternative modes of supportive care and guidance for fragile elderly people, in order to enable them to keep on living at home. Informal caregivers are actively involved in making care arrangements that are tuned to the individual needs and priorities of the patients and their informal care givers [34]. Participants and/or their informal care givers are present at the initial multidisciplinary meeting when the draft care plan is discussed. In this specific project the burden of care that was experienced by informal carer(s) was assessed as part of the total needs assessment of eligible patients [34]. Besides that, informal carers were involved in the development of patients’ individual care plans, which included self-management activities actively supported by their informal carer(s) [34].

Text box 3. Illustration of care coordination

In the visited Gesundes Kinzigtal program the GP is the main care provider and patients are free to choose their physician, which is named ‘doctor of trust’, acting as a health care coach. The introduction of a new professional role (“coordinator”), who will coordinate the care process and support the work of the GP, is currently in development. The Gesundes Kinzigtal program implemented EHRs to support coordination of care, multidisciplinary collaboration, transparency and

improvement in the quality of care. However, it took more than five years to implement shared EHRs [38], which indicates its complexity. The shared EHR, which was integrated into the information system of all participating physicians, is now used by physicians and other care providers involved, such as outpatient nursing care services and hospitals. It was emphasized in the interviews during the site visit that the implementation of the shared EHRs system could only be achieved on the basis of profound mutual trust among providers.

Figure 1. Program selection process

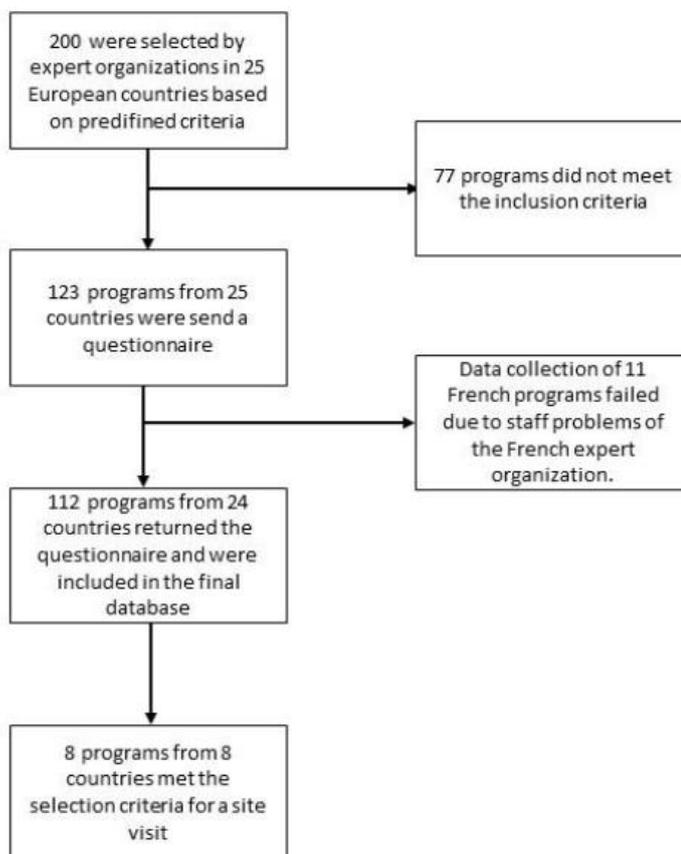


Figure 2. Reported barriers to a patient-centered approach (percentages); N=112 programs (multiple responses were allowed)

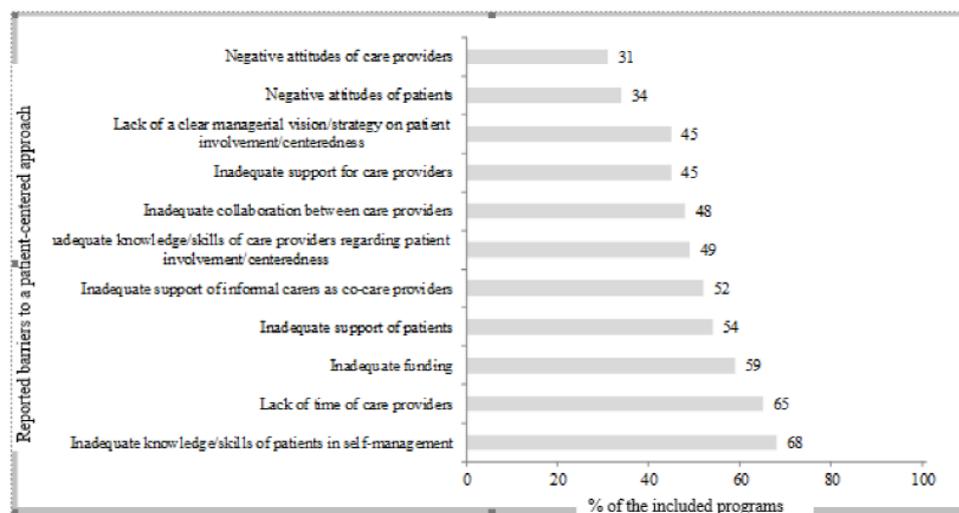


Table 1. Number of programs that address aspects of patient-centeredness (N=112 programs)

Elements of patient-centeredness	Aspects of patient-centeredness	Number of programs
Element 1: responding to patients' needs, preferences and resources in developing individual care plans	Applies methodologies or tools to involve patients in decision-making	99
	Addresses specific subgroups	77
	Provides patient education materials	69
	Develops individual care plans together with patients	80
	Patient education materials adapted to subgroups	21
Element 2: involving informal carers	Informal carers are a target group	46
	Addresses informal carers as co-care providers	30
	Addresses informal carers as co-clients	22
Element 3: coordination and multidisciplinary collaboration	Multidisciplinary collaboration is main objective	88
	Improving care coordination is main objective	80
	Appointing a single care provider for communication with patient	73
	Multi-professional care groups established	77
	Uses a digital communication system to support communication between care providers	44
	Merging of units (within a care organization) established	21
	Merging of care organizations established	25

Green: in 75-100% of the programs; light green: in 50-74% of the programs; orange: in 25 to 49% of the programs; red: in less than 25% of the programs

APPENDIX 1

Table 1. Visited programs by the ICARE4EU partners and date of visit

Program	Country	Visiting partner 1	Visiting partner 2	Date site visit (2015)
POTKU project	Finland	UEF	NIVEL	25-27 Februari
Gesundes Kinzigtal	Germany	TUB	NIVEL	31 March-1 April
TeleRehabilitation programme	Cyprus	INRCA	NIVEL	2-3 April
INCA-model	Netherlands	NIVEL	TUB	14-15 April
Diabetic care Burgas programme	Bulgaria	TUB	INRCA	11-12 May
Strategy for Chronic Care of the Valencian Region	Spain	INRCA	UEF	15-16 April
Clinic for multimorbidity and polypharmacy	Denmark	UEF	TUB	26-27 May
Protocol 3 programme	Belgium	NIVEL	INRCA	28 May and 12 June

DETAILS ON THE EIGHT SITE VISITS

Site-visit POTKU project: Interviews were conducted with the project manager and other actors of the project, representatives of care providers and a representative of a patient family association. In addition, information about the programme, such as

data collected previously by the project, other project documents and external information related to the project were studied. **Gesundes Kinzigtal:** Interviews were conducted with a project initiator, the project manager, a physician, other care professionals and external researchers. Moreover, we received information about future programme plans, we visited the offices of the programme's staff and received brochures and other types of written information about services provided as part of the programme. In addition, documents explaining the model's approach, funding and payment mechanisms, organisational structure, self-management approach and scientific papers describing the evidence of the effectiveness of the programme were studied. **28 Site-visit TeleRehabilitation programme:** Interviews were conducted with the project coordinator, the project manager, a computer scientist, a psychologist and a nurse. Furthermore, information about the technical and organisational aspects of the programme was received and studied. A costbenefit analysis report, available only in Greek language, was translated in English and used as a relevant source of additional information on possible economic outcomes. **Site-visit INCA-model:** Interviews were conducted with the project manager and with a nurse who applied the model as part of a pilot-project. As it turned out during the site visit that the model had not been implemented yet (apart from a very small scale pilot), it was not possible to interview other staff involved. In addition, documents explaining the model were studied. **Diabetic care Burgas programme:** Interviews were conducted with the programme manager, several programme initiators, several volunteers, specialists and patients. Moreover, we received additional programme related information from a local researcher who helped with the translation of the interviews and the organisation of the entire site visit. Furthermore, information about the initiation of the programme, additional training for volunteers, cooperation structures and funding of the programme was received and studied. **Site-visit Strategy for Chronic Care Valencian Region:** Interviews were conducted with the programme coordinators at the Valencian Region, the staff at the pharmaco-economics office, the health staff in three hospitals and two health centres, and patients and family carers. In addition, official documents explaining the policy programme, the care organisation and the implementation of information systems were retrieved from the Valencian Region and healthcare structures, and studied and integrated with the data collected in the interviews. **Site-visit Clinic for multimorbidity and polypharmacy:** Interviews were conducted with the project manager, chief doctor, medical doctor, nurse pathway coordinator, secretary pathway coordinator, clinical pharmacist, physiotherapist, occupational therapist and GP. Furthermore, information about the programme, such as presentations and articles describing the clinic, was received and studied. **Site-visit Protocol 3 programme:** Two projects of the Protocol 3 programme were visited ("Alternative de Soins" and "Som +"). Interviews were conducted with the programme managers and multiple care providers. Furthermore, information about the programme and its subprojects was received and studied.