### ORIGINAL ARTICLE

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# Nurse coordinator of care as a facilitator of integration processes in palliative care

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### **Abstract**

**Aims and objectives:** This paper investigates the feasibility and the perception of the nurse's role as the palliative care coordinator.

**Background:** Integrated care is a global imperative in all healthcare improvement processes. Due to Andrija Štampar's success in the organisation of public health services, Croatia today has more than hundred years of experience in care integration. The palliative care system has been continuously developing since 2014 as an integrated care model, with nurses as care coordinators.

**Methods:** The study used a mixed methodology based on pragmatic research principles, including an analysis of strategic and policy documents and reports, and thematic analysis of focus group conducted with palliative care coordinators, following COREQ checklist.

**Results:** Although a legal, professional and financial regulation of nurse coordinators has been achieved, a number of implementation challenges remain. These challenges arise as a result of long-term fragmentation of the health and social care, and can be found in both horizontal and vertical integration of care, that is in the dimensions of functional, clinical, cultural and social integration.

**Conclusions:** Nurses play a central role in care coordination. Coordination and integration promote professionalisation with clear roles and tasks. However, even with the legal, professional and financial implementation of the nurse coordinator model, it has to be further promoted as an equally important job in the healthcare system, with nurses as competent professionals in charge of care coordination.

Relevance to clinical practice: Palliative care provides a range of individualised, coordinated services that meet the medical and non-medical needs of seriously ill patients. Described model of palliative care in Croatia is particularly important because it was developed as an integrated part of health care (and partly social welfare) system,

indicating with the nurse's role as palliative care coordinator that coordination is a continuous process that requires a dedicated professional role.

#### **KEYWORDS**

care coordinator, integration, nurse, palliative care

### 1 | BACKGROUND

# 1.1 | The global imperative of care integration

Care integration is a coherent set of organisational and clinical methods and models designed to create continuity, coherence and cooperation within and between different care sectors (Goodwin, 2016b). Integrated care brings coherence and synergy between different parts of the health system, thus improving its efficiency, quality of care, quality of life and patient satisfaction, especially for complex patients (World Health Organization. Regional Office for Europe, 2016a). Integrated care is the answer to the biggest shortcomings of modern health care such as difficult accessibility, fragmented care, suboptimal quality, system inefficiency and high costs. These shortcomings are primarily due to high differentiation, specialisation, segmentation and specific way of thinking (so-called silo mindset), deeply embedded in all aspects of the health system (i.e. health policy, regulation, funding, organisation, and professional and institutional culture) (Kodner & Spreeuwenberg, 2002). Furthermore, the orientation of the healthcare system to acute, episodic medical care is less and less meeting the growing needs and increasing number of chronic and fragile elderly patients (Nolte & McKee, 2008).

Integrated care is a global imperative in all healthcare improvement processes. Although it seems as a new trend looking at the policies and priorities of the World Health Organisation (World Health Organization. Regional Office for Europe, 2019), the World Bank (Somanathan et al., 2019), the European Union (Guagliardo & Dhéret, 2019), etc., integration of care is in fact a process that has been developing over the decades with and within health systems. However, the visibility and evaluation of these processes were limited due to the large differences in the organisation of healthcare systems and limitations in the exchange of information between countries (Goodwin, 2016a; González-Ortiz et al., 2018).

### 1.2 | History of care integration in Croatia

The Republic of Croatia has more than hundred years of experience in the field of care integration. The first successes were achieved in the field of public health interventions led by Andrija Štampar during 1920 (Horton, 2016). In the early 1950s, health centres were formed in primary health care as an integrated form of care provided in healthcare institutions. The next step was to initiate specialisation and form family medicine offices designed to integrate care at

# What does this paper contribute to the wider global clinical community?

- Integration and coordination are key challenges and solutions for the emerging complex needs of patients.
- Modern health care with its complexity gives a new role to nurses and emphasises the importance of their professional competencies.
- This paper indicates the areas to invest in order to implement the new nursing role, and hence the integration of care.

the community and family level (Expert Network on Family Practice Development Strategies & WHO Regional Office for Europe, 1998). Within this model, a family doctor and a community nurse worked together as independent professionals responsible for a specific population, that is for a specific community. With the development of the health promotion concept, the Republic of Croatia became one of the pioneers of the World Health Organisation's Healthy Cities project (World Health Organization. Regional Office for Europe, 2009). Long history and rich experience form a good basis for the development of new forms of integration; however, many challenges still remain for successful integration. This can be a particular problem in the matter of new and specific care needs or when connecting more sectors and professions, as it is the case with palliative care. However, despite being insufficiently researched within the Croatian healthcare system, the understanding of the role and evolution of nursing profession in relation to the development of palliative care has finally come to the fore (Kralj et al., 2018).

# 1.3 | Current organisation and implementation of palliative care in relation to care integration

The World Health Organization (2020) defines palliative care as 'an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'. Palliative care is one of the most delicate and complex forms of care (Pask et al., 2018). As well as other forms of long-term care, it has integration as a fundamental principle (Payne et al., 2022; Radbruch &

Payne, 2009). The characteristic of the population of palliative patients is that they generally have many conditions that do not fit into clear categories of diseases based on divisions by organs, but rather have multifactorial causes. Examples include cognitive impairment, delirium, incontinence, malnutrition, pressure ulcers, sleep disorders, sensory deficits, fatigue, stench and immobility. Social factors, which mutually worsen with health factors, such as reduced income and poverty, social isolation and the lack of reliable persons to trust, are as well often present. Therefore, without integration of health care, social services and Non-Governmental Organisations (NGOs), it is not possible to organise and provide quality palliative care (Kaasa et al., 2018).

In the Republic of Croatia, the palliative care system has been continuously developing since 2014. Its development is entirely based on the principles of integration of existing resources. Through the implementation of the Palliative Care Development Strategy 2014, the necessary legislation and clear professional guidelines have been made, and financial resources have been provided for care coordinators to be contracted in all counties (Lončarek et al., 2018). As such, the integrated model of palliative care in the Republic of Croatia represents a unique example of full application of the model of integration of care that has given clear positive results (Vočanec et al., 2022).

# 1.4 | The role of a nurse as a palliative care coordinator

Care coordination is a means to achieve integration of care, in which nurses play a central role. According to Karam et al.'s review (2021), there is a heterogeneity of activities within the role of a care coordinator, which depend on the context, target population and set goal. Clarfield et al. (2001) argue the need for comprehensive systematic enabling of care coordination as opposed to isolated micro-level attempts.

In Croatia, palliative care coordinators were introduced with the aim of working on the active development of the palliative care network—horizontal integration of stakeholders in primary health care (PHC) and vertical integration towards the hospital system on the one hand, and social and civil society on the other. It is an attempt to integrate care processes by facilitating cooperation between all stakeholders involved in providing palliative care.

With the implementation of the Palliative Care Development Strategy in the Republic of Croatia (Ministry of Health, 2014), their role is regulated by the Health Care Act and bylaws (Health Care Act, 2018), professional competence requirements and role description (Marđetko & Dumbović, 2017), and financially through defined diagnostic-therapeutic procedures used for monitoring and evaluation of their work (Croatian Health Insurance Fund, 2015).

The aim of this paper is to investigate the opportunities and obstacles for the implementation of care integration and the nurses' performance as care coordinators in the Republic of Croatia. In other

words, the paper examines whether the role of a care coordinator is feasible and how the nurse is perceived in such a role.

### 2 | METHODS

The study used a mixed methodology (Hansen et al., 2016; Tariq & Woodman, 2013) based on pragmatic research principles (Brierley, 2017; Kelly & Cordeiro, 2020), and following Consolidated criteria for reporting qualitative research checklist (Appendix S1). We have explored multiple levels of the implementation of palliative care model in the Republic of Croatia. In view of the fact that it is a model based on care integration, we conducted a research examining integration processes. The research consisted of two components:

(I) The national and strategic documents (Ministry of Health, 2017, 2021) formed and adopted after the Palliative care strategy, and available national and county reports (Croatian Health Insurance Fund, 2021; Commission of the Ministry of Health for Palliative Care, 2019; Huić et al., 2016; The World Bank, 2019) were analysed (Bowen, 2009) to demonstrate the course of changes.

In the reports, we identified key quantitative results presenting the implementation of care integration and role of nurses as care coordinators. In this regard, the implementation of the palliative care model and the role of nurses as care coordinators were analysed through the presentation and analysis of available information according to the Donabedian's quality model (Donnabedian, 2005), that is the structure, the process and the outcome of palliative care.

(II) Through focus groups conducted with palliative care coordinators, we examined how the integration of care and the role of nurses as care coordinators are understood and practically implemented. The author (DV) sent an e-mail invitation for participation in focus groups to all 21 counties' coordinators official e-mail addresses. The inclusive criterion for participation was that the person is employed as a palliative care coordinator at the county health centre, with a minimum of one-year experience. As a group of actors in palliative care, they represent health professionals involved in the operational organisation and management of long-term care. By profession, they are graduate nurses or nurses with bachelor's degree, with additional education in palliative care. Sixteen coordinators responded in the affirmative, with whom two focus groups were conducted. Focus groups were conducted online, via Zoom platform, lasting 90 minutes each. The conversations were recorded and transcribed verbatim. The conversations were attended by a fellow observer, who took notes and checked the transcripts. Prior to the research, all participants gave their informed consent for participation in the research. The study was approved by the Ethical Board of the University of Zagreb School of Medicine, as part of doctoral research 'Determinants of the long-term care integration process in the Republic of Croatia based on a palliative care model'. The focus groups followed a structured scheme, developed by the authors and based on the prior research (Vočanec et al., 2022). At the beginning,

the facilitator (DV) explained the context and the specific aims of the focus group.

In the qualitative thematic analysis (Braun & Clarke, 2006, 2014) of the transcripts, performed by two of the authors (DV, ADž), we used the prism of different dimensions of integration, primarily the breadth of integration, the functional and clinical type of integration, and the integration process. By the breadth, integration can be seen as horizontal, integrating care delivery at the same level of care, and vertical, integrating care delivery among different levels of care and different care sectors. The functional integration refers to financial management, human resources, strategic planning, information management and quality improvement being coordinated across operating units, whereas clinical integration is about harmonised care processes, tools and guidelines, and functions and activities used by different professionals. The integration process includes cultural and social aspects, weighing the similarities and differences in the system of established values, norms or goals among the parts of the system that are being integrated (RAND RAND Corporation & Ernst & Young LLP, 2012).

### 3 | RESULTS

### 3.1 | Establishment of the system

Palliative care development strategy 2014-2016 and the successive National palliative care development plan 2017-2020 have led to changes in laws and regulations, as well as in documents that determine the business practice in health care such as the Plan and program of healthcare measures. Basics for contracting health care. and Public Health Service Network. The principles of palliative care organisation (Table 1) emphasise the need for a comprehensive and integrated approach to palliative care, that is the palliative patients' needs. This implies changes predominantly at the level of care process (as opposed to changes in the organisational structure). A key novelty in the health system, with regard to the organisational model of palliative care, is the palliative care coordinator. The strategies resulted in legal, professional and financial regulation of the role of the coordinator. This is the first (and only) such role, arising from the need to emphasise the importance of care process in integration and its facilitation. By formalising the role of the palliative care coordinator (Table 2), the complexity of palliative care has been acknowledged and the present fragmentation of services admitted. Furthermore, the need for the integration of care has been confirmed in the National healthcare development plan for the period from 2021 to 2027. The situational analysis of the healthcare system addresses the high segmentation and system-centred organisation and practice of health care. In response to this situation, the development needs include coordination of care providers, active management of the care process through all levels (primary-tertiary) and segments (prevention-palliative care) and comprehensive consideration and response to patients' needs in the field of health and social care. In addition, public policy priorities include strengthening

TABLE 1 Principles of palliative care organisation in the Republic of Croatia

	Structure	Structure		
	Space	Equipment	People	
Financing		Processes		Education
	existing element of the procedure of the	resion of existing ces, empowern ining of professe establishmen ures and stand appeared of additional appeared of additional appeared of additional appeared of additional appeared of a systems and in gresources uously and in gresources uously and in gresources uously and in gresources and forms of produces, encourts all forms of rizontal cooperstrong cross-sections will be additional appeared of a section appeared	g spatial nent sionals, to finew lards of tional nodels le to ve care inproving partnership of other alliative ages and vertical ration, as ectoral libit to the dence in rve social mining the re must be Croatia	
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Source: Authors, based on Ministry of Health, 2014.

of primary health care, care provision in close proximity to the patient (at home and in the community), and improvement of stewardship and management capacities by establishing an information management system, which is a prerequisite for coordination and integration of care.

# 3.2 | The role and position of the palliative care coordinator in the system

The implementation of the palliative care model outlined in the strategic plan has been delegated to the county level. This follows the formal-legal relations related to the ownership and competence in the organisation of health care. The intent is to respect and adapt the model to local (county) specifics in accordance with demographic,

TABLE 2 Palliative care coordinator's defined diagnostic and therapeutic procedures, funded by the Croatian health insurance Fund

stakeholders in palliative care, at the local and national level government; health institutions; social institutions care providers; non-governmental organisations; norgovernmental orga	
3. Coordination of continuous care for the palliative patient and family in different places and levels of care services and institutions escribing and topogration with services and institutions palliative care, organising group and individual meters; organisations and their involvement in systematic care at the local and national level organisations and promotion of palliative care, at the local and national level organising individual and group meetings, and cooperation with other stakeholders in palliative care, at the local and national level organising individual and group meetings with other stakeholders in palliative care, at the local and national level organising individual and group meetings with services.  8. Education and promotion of palliative care through evidence-based research papers  9. Connecting with the scientific community and institutions for education and participation at the national level of palliative.  10. Cooperation and participation at the national level of palliative care profusion and procedures; evaluation organising individual participation and profusion an	ssionals; ng a
for the palliative patient and family in different places and levels of care; making and implementation of a pate of care are the place of care; making and implementation of a pate of palliative care services and institutions and institutions palliative care, organising group and individual men professionals and volunteers; organising supervisis and spiritual care  6. Connecting and cooperating with local health services, social and spiritual care organisations and their involvement in systematic care organisations and their involvement in systematic care stakeholders in palliative care, at the local and national level palliative care providers; non-governmental organisations; norganisation and prometing with other stakeholders fregional government; health institutions organisation and promotion of palliative care through evidence-based research papers evidence-based research papers or education and volunteers; organising public rallies that promotion of community and institutions for education and vocational training  10. Cooperation and participation at the national level of palliative, protocols and procedures; evaluation or guidelines, protocols and procedures; evaluation or guidelines.	eiving aids;
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stakeholders in palliative care, at the local and national level government; health institutions; social institutions care providers; non-governmental organisations; norgovernmental orga	orating ling to
palliative care through evidence-based research papers and volunteers; organising public rallies that promo advocate for palliative care  9. Connecting with the scientific community and institutions for education and vocational training  10. Cooperation and participation at the national level of palliative grants and conducting training organisation and conducting training and volunteers; organising public rallies that promo advocate for palliative care  Organising and conducting education, conducting practical classes, mentoring, collaborating in research  Cooperation with competent bodies when drafting organisation and conducting training for profession and volunteers; organising public rallies that promo advocate for palliative care  Organising and conducting education, conducting practical classes, mentoring, collaborating in research  Cooperation with competent bodies when drafting organisation and volunteers; organising public rallies that promo advocate for palliative care  Organising and conducting education, conducting practical classes, mentoring, collaborating in research  Cooperation with competent bodies when drafting organising public rallies that promo advocate for palliative care	and local ; spiritual nedia;
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the national level of palliative guidelines, protocols and procedures; evaluation o	etical
development care care work and development	
11. Planning the development of Creating an annual plan palliative care in a particular area	
12. Preparation of an annual report including the evaluation of the work of the coordinator and mobile palliative care team  Reports are sent to the competent regional office/regional office	

Source: Marđetko & Dumbović, 2017.

geographical, socio-economic circumstances and available resources, as opposed to the one-size-fits-all national model. In addition, it was proposed that coordinators become members of county palliative care development teams.

Practically, the county government is the founder of health institutions at the primary and secondary level of health care and is therefore responsible for establishing the number of coordinator(s), defined by the Public Health Care Network. Since 2015 until today, 42 coordinators have been contracted at the level of the Republic of Croatia, of the required 52. All counties but one have a minimum of one coordinator. Coordinator performance monitoring is done through monthly reports on the implementation of defined diagnostic and therapeutic procedures (Table 2). However, it is difficult to assess the reliability of such numerical reports due to the fact that

traceability of the work process is not defined. In other words, monitoring of the quality of work within these diagnostic and therapeutic procedures has not been established yet.

# 3.3 | Opportunities and obstacles in the work of palliative care coordinators

The main goal of the organisation of palliative care is to ensure the comprehensiveness and continuity of care that meets the needs of the patient and its family. There are two integration axes to achieve these goals. One is horizontal, which refers to the integration of resources and processes at the same level of care, in this case primary health care. The other is vertical, involving the integration of resources and processes at different levels of care (primary, secondary and tertiary level of health care) and cross-sectoral: formal-informal care, and health-social care. Regarding these dimensions of integration of care, the following themes emerged in the analysis of focus groups' transcripts:

### 3.3.1 | Horizontal integration

Horizontally, at the level of PHC, palliative care services can be provided by a family doctor, community nurse, home care nurse, mobile palliative care team (doctor and nurse), palliative care coordinator and emergency medical staff (doctor and nurse). Desirable outcome of horizontal care integration is comprehensive and holistic care. On that horizontal axis, the coordinator has the role of care manager. Depending on the needs of the patient (and its family), it engages available resources and organises care according to the 24/7 model.

In achieving horizontal integration of care, elements of cultural and functional integration stand out among the obstacles.

# 3.3.2 | Acceptance of coordination as an equal work in health care

The lack of staff employed at health centres, and frequent replacements affect the daily organisation of work. This represents a problem particularly at a time when vacation leave is traditionally used more often, for example during the summer season or festive period around Catholic Christmas and New Year's Day. An additional shortage of staff was caused by the COVID-19 pandemic due to additional work activities aimed at curbing the epidemic and more frequent sick leave as a result of isolation and quarantine measures for medical staff. Therefore, palliative care coordinators were oftentimes also employed as substitutes in mobile palliative care teams or as community nurses, leaving their primary function empty, that is fulfilling it along the way or in their spare time. This practice is perceived as a lack of understanding and low perception of the importance

of coordinators in palliative care by the management of the health centre.

The idea is that integrated care should be focused on the patient, and our actions are in part aimed at coordinating all the necessary activities so that they are in some way synchronized and that patients do not have to organize care for themselves. Unfortunately, we do not have the support of our institutions; most of our colleagues know that everyone still regards us [nurses] as patches that cover up all the holes that exist in a particular institution.

(Nurse coordinator 3)

And as for the job, we were patching holes in the Covid infirmaries taking swabs, replacing the mobile team nurses, community nurses and so on.

(Nurse coordinator 7)

# 3.3.3 | Accepting the nurse as a professional who coordinates the stakeholders

In the relationship between different professionals, a hierarchical structure is expressed which makes teamwork more difficult. This is seen in the doctor-nurse relationship, but also among nurses with different levels of education.

The engagement of resources (in this case, professionals providing care) is based on the coordinator's assessment and is carried out operationally by making requests and orders, either through an information system, by email or telephone. A number of family physicians are more inclined to communicate and cooperate directly with the doctor from the mobile team rather than with the coordinating nurse.

I know some [family] physicians who refuse to cooperate with the coordinator, who directly report the patient to the mobile palliative team because they think they can better communicate their needs with the physician. But it is coming, this cooperation with doctors is gradually improving, all for the better care of our patient.

(Nurse coordinator 10)

There is less cooperation with community nurses because there is a dispute over who should report and inform about the patient.

(Nurse coordinator 5)

If you call a family physician for anything, it will depend on his good will whether he will listen to you or not, not to mention that as far as the home care nurse and community nurse are concerned, it's all a matter of good will whether they will come to the patient's home the same day or not.

(Nurse coordinator 3)

Some coordinators are making an effort to improve these relationships by going door-to-door to family physicians and familiarising them with the scope of their work. This is demanding and time-consuming in larger urban areas where there are many family physicians, most of whom have individual private practices providing services under compulsory health insurance and are not employees of the health centre. As some of the coordinators previously worked as community nurses or are currently employed as head nurses of the health centre, they already have established relationships and connections with many stakeholders involved. Where social contacts are stronger, cooperation is easier.

I don't know if it's because of my experience, profession or knowledge of the complete structure of people working in the health care system in my county, but I can say that the admission was quite ok. And after a year when they [family physicians] realized that in principle, palliative care does not take away their fees nor patients, but provides enormous help, the response became higher.

(Nurse coordinator 14)

I think it depends on where you worked, what you did and how many people you know.

(Nurse coordinator 13)

# 3.3.4 | Defining competencies in the business aspect of providing care

In-home care can be provided by six primary care nurses: a nurse from the family medicine team, a nurse from the emergency medical team, a nurse from the mobile palliative care team, a community nurse, a palliative care coordinator and a home care nurse. They differ in their levels of education (secondary, undergraduate, or graduate and postgraduate education) and thus in their competencies. However, in some procedures that are within the common competence of all nurses, there are administrative restrictions on their implementation. In other words, the system of diagnostic and therapeutic procedures, defined by the Croatian Health Insurance Fund as a payment model, is not fully in line with professional competencies, but rather subordinated to the theoretical care scenario, not considering 24/7 need-based care model. Such practice leads to a waste of resources and creates frustration.

It seems to me that we are wasting too much resources and energy. For example, three nurses go

to home visit on Friday: a home care nurse, a community nurse and a nurse from the palliative mobile team. The nurse from the mobile team administers a medicine for nausea [subcutaneously]. On Saturday or Sunday, the family will administer the medicine. On Monday, the home care nurse will go to home visit again. However, she is not allowed to administer the medicine, neither is the community nurse, while the family is! Therefore, it seems a bit unreasonable to send three nurses in one day to administer one medicine. It totally drives me crazy.

(Nurse coordinator 2)

It is well known who is allowed to do what. The weekend is coming, everything is changing, and everything goes down the drain. While things are different on paper and the law says differently, in reality, you have more people taking care of one patient, you have a home care nurse, you have a community nurse, everyone thinks they know best, and everyone will give their advice, their recommendation on how to treat some pressure ulcers, for example. A nurse from the mobile team comes; she will give a third piece of advice. People are confused, and we are the ones on the phone, reading the law... and the patient remains unattended and that's not good.

(Nurse coordinator 1)

### 3.3.5 | Vertical integration

Desirable outcome of vertical integration of care is continuity of care between different levels and places of care (e.g. between home and hospital care). In the context of multisectorality, which is characteristic of palliative care, vertical integration includes social workers, clergy, NGOs (RAND RAND Corporation & Ernst & Young LLP, 2012).

The patient moves intermittently along the vertical axis of care, for example when acutely experiencing any of the symptoms that cannot be taken care of at home or exercising the right to a certain benefit, the purchase of aids, etc. On this axis, the coordinators have administrative role, that is ensuring the continuity of information and relationships. Their role is mostly realised in the process of discharge and admission of the patient to the hospital, in exercising rights from social welfare or involving volunteers through NGOs.

Obstacles in the vertical realisation of care arise from the dimensions of functional, clinical, cultural and social integration.

# 3.3.6 | Acceptance of palliative care philosophy

Acceptance of the palliative care philosophy includes a holistic biopsychosocial approach instead of a biomedical one, and acceptance of dying as an integral part of life. Although the patient can receive palliative care even during the active treatment, in practice the care is provided to the patient after the end of active treatment, in the terminal phase of the disease. There is reluctance on the part of hospital physicians, family physicians and even the patient's family to communicate the inevitability of death and to refer the patient to palliative care. This often results in the coordinator being contacted days to hours before the patient dies, which is too late for purposeful care.

So, I think that in fact we should start from the beginning with the sensitization of medical staff. It is important that people know who we are and what we do in order to involve us from the beginning and not think that palliative care starts when the curative treatment is over. Unfortunately, we get all the patients too late, when physical symptoms have already started, and unfortunately, we are seen by other professionals as if we are only in charge of these physical symptoms and not of solving other problems.

(Nurse coordinator 3)

What I noticed after so many years is that our doctors have a hard time deciding to refer a patient to palliative care. And it is much more difficult when it comes to a malignant disease. A colleague, present here [in focus group], previously said that the average in care is 17 and half days, so it often happens that we get a request for palliative care today, and the patient dies tomorrow.

(Nurse coordinator 16)

### 3.3.7 | Information management

In the last year of life, it is difficult to predict when a patient's health condition will worsen and who will be available to him at that point. Under such circumstances, patients are constantly changing the environment in which they receive care, which brings with it an accumulation of information. Due to the incoherence of information systems, significant amount of time is spent on repeatedly collecting and deciphering important information about the patient. Part of the documentation is integrated, such as an e-referral, e-prescription or more recent e-discharge letter. However, these are medical records, while nursing records are by no means systematically integrated between two nurses performing the same or different tasks.

From the physicians working at the hospital, we only have a recommendation for palliative care written in the discharge letter or on the outpatient sheet, which includes our landline number which the family should call. Since they [family] should show every discharge letter and outpatient sheet to their family physician,

the hospital physician believes that he has resolved the matter with this recommendation. However, this is not always the case.

(Nurse coordinator 10)

The family physician didn't visit him [the patient] either, and I almost made a recommendation [for stationary accommodation] based on an e-mail correspondence, when at the very last minute I have remembered not hearing from home care nurse, so I called her

(Nurse coordinator 9)

When our mobile team does a home visit, they always leave behind a written finding for the patient, the family, which includes not only anamnesis and provided examinations, but also a recommendation. So in essence, the family can take to their physician in writing what our physician recommended, and of course, if we communicate by phone and no visit is made, then we instruct them to contact the family physician and if the physician has any doubts, he can always contact us directly.

(Nurse coordinator 12)

### 3.3.8 | Proactive attitude towards work procedures

Legal regulations—so-called ordinances refer to procedures broader than the clinical aspect and are related to business and administrative monitoring of the work of health professionals, in relation to the patient and other professionals. There are differences in the interpretation of such procedures, which can result in large variations in the care process and suboptimal care delivery. A number of coordinators fear inspections in the case of a proactive approach to procedures that would meet the real needs of patients, but would also mean stepping out of the traditionally established ways of work.

As a coordinator at the health centre, as a rule, we do not go to the field (...) the first thing is, we are not even paid for field work, we are placed in the office.

(Nurse coordinator 10)

I will just say that I think that we [coordinators] who go to home visits do not make mistakes because there is this code KP003 that says home visits. I am of the opinion that our job is to do everything in the home environment for that patient. We will see...

(Nurse coordinator 5)

Today, unfortunately, we have to be careful because we know that both patients and families are prone to various lawsuits...but we are not rigid, we will not strictly obey... If there is a need for the mobile team to urgently go to a home visit, they will go, and we, as coordinators, will cover this second part of the job, the paperwork.

(Nurse coordinator 8)

Others believe that this is exactly the way to introduce needed changes in the care delivery process, as long as their actions can be clearly argued from the professional standpoint.

> So, in truth we have no special fears. We had different supervisions. First of all, I think it is extremely important to write down what we did and how we did it. That's why our teams leave a written trace behind, because then there is a document that someone did something. I think that the only thing that matters is that we work within our competencies and do not do something what we are not educated for. I think if you explain it to, either the supervision of the professional Chamber or the supervision of the Ministry, or the people who do their jobs as experts, it will be clear to them. Because only in this way some rules of procedures can be changed - if we have arguments, evidence, some statistical data why it was done so.

> > (Nurse coordinator 11)

I carry out professional supervision for the Chamber and for the health centre, I have been working for 37 years. It has never happened that the lawsuit came from a patient or anyone else because something was done but rather because something was NOT done.

(Nurse coordinator 9)

The social welfare system is highly regulated and slow to respond to requests, in terms of exercising the right to benefits, etc. When it comes to palliative patients, such inflexibility could lead to patient's inability to exercise their right while in need or alive.

> Unfortunately, from our point of view, at least in our county, the social welfare centre is relatively bureaucratic, and they require a lot of documentation.

> > (Nurse coordinator 11)

It is also a problem that the patient unfortunately dies before exercising some rights, due to the fact that this fast line does not yet exist. Moreover, what represents a problem during vacations is that there is no staff replacement, meaning that the patient has to wait until the respective colleague returns, in four weeks.

(Nurse coordinator 3)

Palliative patient's time is literally running out and if you can't quickly achieve something for that patient, whether it's a request for financial aid, for caregiver's help - it takes time for the request to be processed, regardless of the social worker's performance. So many times it happens that you lose the patient in the meantime.

(Nurse coordinator 4)

# 3.3.9 | Establishing professional interinstitutional links

Efforts to overcome such backlogs and bottlenecks in the process of care are based on personal acquaintances and treated individually case-by-case. Little is being done to systematise and up-scale them to the level of inter-institutional cooperation. By replacing a person in a position, the establishment of cross-sector or inter-institutional cooperation starts from scratch.

> We spend all our resources, we bore all our friends who are physicians and nurses by profession to do something. We do it so often that they ask us every day how many relatives, grandmothers, aunts, uncles...we had. Because that is how we get away with it, by saying that it is someone of ours.

> > (Nurse coordinator 9)

For example, I know the director [of the Centre for Social Welfarel personally. Therefore, I personally go to solve some things and then they are solved faster. But it [faster procedure for palliative care patients] doesn't exist officially, it doesn't exist within hospitals, it doesn't exist within private nursing homes, it simply doesn't exist. All is based on "Please" and "Thank you", and for a packet of coffee I buy.

(Nurse coordinator 10)

### **DISCUSSION**

The Republic of Croatia has a long tradition and rich experience in integration, but only through the palliative care reform is it regulated and conducted comprehensively. A strong emphasis on the integration of care, especially long-term care, has been stated, through European policies, as well as in Croatian strategic documents. (Ministry of Health, 2021). This is happening at a time when the results of palliative care reform in Croatia, which began in 2012, are being seen (Lončarek et al., 2018; Vočanec et al., 2022). In this comprehensive reform, the role of coordinator has been created with the goal of implementing the integration of the care process. An earlier attempt to integrate palliative care was at the level of structure when the establishment of a palliative care facility that was legally

allowed, and envisaged to be an integration factor and driver of palliative care development, proved ineffective.

Today, many stakeholders are involved in care (Nolte & McKee, 2008), especially when it comes to palliative care because the needs are in the domain of psychological, spiritual, health and social care (Radbruch & Payne, 2009). On the one hand, more stakeholders can respond to specific needs in a specialised way, while on the other hand, this increases the complexity of the care process (Pask et al., 2018) and opens the need for coordination of all these stakeholders, that is process integration. When there is no coordination of care providers, there is a paradoxical situation that with more resources, the efficiency of care is lower (Frandsen et al., 2015). If care does not work horizontally, the episodes, the vertical movement of the patient through the system is more frequent. An increase in the number of such episodes is expected in the last year of life (Normand et al., 2021). In the traditional view of the care process, the analysis is done from the perspective of an individual care provider. With such a static and segmented approach, it is difficult to identify the problem. Only by looking at the care process from the patient's perspective, as an actor who is the link to all other actors, we get an insight into comprehensive care, according to the 24/7 model—overlaps, holes and bottlenecks (Antonacci et al., 2018). It is, in essence, the job of the palliative care coordinator to put all stakeholders in a spatio-temporal relationship, according to the patient's need. The concept of the integration of care confirms and brings at the fore some of the core principles of nursing profession, such as care for the person and advocacy for the patient (Raatikainen, 1989; Royal College of Nursing, 2022). The example of Croatian palliative care model shows how these principles could be shaped into clear work tasks.

The obstacles in the achievement of the integration of care after the legal, professional and financial prerequisites have been met, arise from the process of this conceptual change, that is a reorientation from the system-in-the-centre to the patient-in-thecentre, followed by change in some established ways of working (Kozlowska et al., 2018; World Health Organization. Regional Office for Europe, 2016b).

There are structural assumptions that stem from the tradition of the health system—its organisation and the relationship between stakeholders, which complicate the integration process. One such relationship is the doctor-nurse relationship, which is traditionally hierarchical. In palliative care, such a relationship is inapplicable because it is the nurse who is providing care for the patient most of the time and considers overall needs, and therefore she decides when to include the doctor in care, not the other way around. In systematic reviews (Maier et al., 2017), an equivalence between nurse-led and physician-led care is shown in respect of clinical effectiveness, and a higher patient satisfaction in nurse-led care, for a number of chronic diseases. Besides this, a role ambiguity (Nutt & Hungerford, 2010) and perceived role overlap (Drennan et al., 2011; Gross et al., 2019) between nurse coordinators and family physicians, and nurse coordinators and community nurses pose a challenge in implementation. The ambiguity of the roles in the palliative care, especially the

question of who should coordinate care, has also been noted among specialist physicians (Cherny et al., 2003; Han & Rayson, 2010).

In addition to the alienation of professionals, the long-term fragmentation of the health (and social) care system has consequently led to the fragmentation of information critical to care planning and coordination (Grunfeld & Earle, 2010; Protti, 2009). In modern times and modern health systems, information is considered an important resource and means of work, with clear and timely communication positively affecting the quality and outcomes of care. Still, we encounter difficulties such as lack of information, different interpretation of information, repeated collection of the same information or information that is not collected for the purpose of decisionmaking. Moreover, patients see informational continuity as an important element in end-of-life care (Michiels et al., 2007). In this sense, it is necessary to develop and conjoin both the format and content of communication between different professionals (Meaker et al., 2018). The need for interprofessional cooperation is perhaps nowhere more emphasised than in the description of the activities of the palliative care coordinator. The underdevelopment of interprofessional networks was reflected in the coordinators' statements. Defining care pathways and team processes might be a way forward (Scaria, 2016; Xyrichis & Lowton, 2008).

#### 5 | CONCLUSIONS

Palliative care emerged as a humanitarian and informal care response to the need to alleviate suffering of the dying. By its recognition and entering in the field of health care, it relies mostly on nursing care. On the other side, integration of care originated from the aspect of healthcare management. In practice, through the role of coordinator, this concept affirmed the already existing nursing principles and converted them into a set of holistic care tasks, putting nurses at the centre of care coordination.

Even with the legal, professional and financial implementation of the nurse coordinator model, critical elements in the implementation of the practice itself are recognition of the new role of the coordinator as an equally important job in the healthcare hierarchy and nurses as competent professionals who can coordinate the work of other stakeholders.

Continuous improvements in information management, development of interprofessional networks and proactive attitudes towards guidelines in health care could to be main opportunities to support and further develop the role of a nurse as a care coordinator.

### 6 | RELEVANCE TO CLINICAL PRACTICE

The paper is important because the experience of palliative care development in the Republic of Croatia is an excellent model for the development of long-term care in general, as well as for formulating long-term care development policies. Palliative care provides a range of individualised and coordinated services that

meet the medical and non-medical needs of the seriously ill and disabled and their families over a long period of time, in a variety of care settings. Palliative care is aimed at maximising the patient's independence and quality of life. In doing so, it engages and coordinates professionals, laypeople and volunteers, with nurses playing a central role—both as coordinators and as providers. All these characteristics also apply to long-term care. The described model of palliative care development in the Republic of Croatia is particularly important because it indicates how it was developed as an integrated part of the health care (and partly social welfare) system, and not as a parallel system or humanitarian aid funded by donations. The role of the coordinator in the palliative care system indicates that the coordination of care is not a 'product' that is given once and no longer requires engagement, but a continuous process that requires a dedicated professional role.

#### **CONFLICT OF INTEREST**

The authors declare that they have no conflict of interests.

#### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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#### SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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