

ID-PALL: An Instrument to Help You Identify Patients in Need of Palliative Care



ID-PALL: Ein Instrument, das bei der Identifizierung von Menschen mit Palliative-Care-Bedarf unterstützt

Fabienne Teike Lüthi¹, Mathieu Bernard¹, Claudia Gamondi^{1,2}, Anne-Sylvie Ramelet³ and Gian Domenico Borasio¹

¹Palliative and Supportive Care Service, Lausanne University Hospital and University of Lausanne, Lausanne

²Palliative and Supportive Care Service, Istituto Oncologico della Svizzera Italiana, Bellinzona

³Institute of Higher Education and Research in Healthcare, University of Lausanne and Lausanne University Hospital, Lausanne

Abstract: Palliative care is frequently associated with the end of life and cancer. However, other patients may need palliative care, and this need may be present earlier in the disease trajectory. It is therefore essential to identify at the right time patients who need palliative care and to distinguish between those in need of general palliative care and those for whom a referral to specialists is required. ID-PALL has been developed as an instrument to support professionals in this identification and to discuss a suitable palliative care project, in order to maintain the best quality of life for patients and their relatives. Recommendations for clinical practice are also proposed to guide professionals after the identification phase.

Keywords: Identification, palliative care, ID-PALL, interprofessional

Zusammenfassung: Palliativmedizin wird häufig mit dem Lebensende und Krebserkrankungen in Verbindung gebracht. Es gibt jedoch auch andere Menschen, die eine Palliativversorgung benötigen, und dieser Bedarf kann bereits zu einem früheren Zeitpunkt des Krankheitsverlaufs vorhanden sein. Daher ist es wichtig, Menschen, die eine Palliativversorgung benötigen, zum richtigen Zeitpunkt zu identifizieren und zwischen denjenigen zu unterscheiden, die eine allgemeine Palliativversorgung benötigen, und denjenigen, die eine Überweisung an Spezialistinnen und Spezialisten benötigen. Das ID-PALL-Instrument ist entwickelt worden, um Fachleute bei dieser Identifizierung und bei der Erörterung eines geeigneten Palliativpflegeprojekts zu unterstützen, damit die bestmögliche Lebensqualität für Patientinnen und Patienten sowie ihre Angehörigen erhalten werden kann. Es werden auch Empfehlungen für die klinische Praxis gemacht, um die Fachkräfte nach der Identifizierungsphase anzuleiten.

Schlüsselwörter: Identifizierung, Palliative Care, ID-PALL, interprofessionell

Résumé: Les soins palliatifs sont d'habitude associés à la fin de vie et au cancer. Cependant, d'autres patients peuvent avoir besoin de soins palliatifs, et ce besoin peut être présent plus tôt dans la trajectoire de la maladie. Il est essentiel d'identifier les patients qui ont besoin de soins palliatifs et de distinguer entre ceux qui ont besoin de soins palliatifs généraux et ceux pour lesquels une orientation vers des spécialistes est nécessaire. L'instrument ID-PALL a été développé pour soutenir les professionnels dans cette identification et pour discuter d'un projet de soins palliatifs adapté, afin de maintenir la meilleure qualité de vie pour les patients et leurs proches. Des recommandations pour la pratique clinique sont proposées pour guider ensuite les professionnels.

Mots clés: Identification, soins palliatifs, ID-PALL, interprofessionnel

Introduction

Peter is a 75-year-old man in good physical health who was diagnosed with Alzheimer's dementia two years ago. Due to his cognitive disorders, he requires home care in order

to fulfil his wish to remain at home. He has fallen twice in the last 3 months and was hospitalised for a broken wrist in the last fall. After acute speech problems ensued, he was hospitalised for a stroke one week ago. He has no motor sequelae, but verbal communication is very difficult, and

he is no longer able to say what he wants for himself. He refuses to eat and has no documented advance care planning or directives. The family does not know whether to accept a feeding tube or not. Do Peter and his relatives require palliative care? If so, do they need general or specialised palliative care?

Despite the development of palliative care over the past few decades, timely identification of the need for palliative care is still a challenge for professionals. This is particularly true for patients with non-oncological diseases, including elderly and demented patients, as well as for patients from vulnerable or minority populations, for whom the need for palliative care is identified too late, or in some cases not at all [1, 2]. Improving access to palliative care for everyone who needs it, regardless of their diagnosis, age, origin or place of care, is an ethical imperative [3].

General versus specialised palliative care

Palliative care can be divided into two categories: general and specialised [4]. The first refers to patients with a chronic, progressive, incurable and life-threatening disease, or who have reached the end of their life, with problems that can be managed by non-specialized healthcare and socio-educational professionals. General palliative care should be initiated not only in the early stages of an incurable disease, but also in cases of significant age-related frailty [5, 6]. In Switzerland, the latter category comprises mainly elderly people living at home or in residential care. The population of patients requiring general palliative care has been estimated to represent 75–80% of patients in palliative situations [7, 8, 9, 10]. The remaining patients have complex needs, including unstable clinical conditions, unpredictability of the disease course and/or high level of bio-psycho-socio-existential suffering [10, 11, 12]. The complexity of these situations requires specific treatment and care by specialists in a specialised palliative care unit or by professionals in mobile palliative care teams [8].

It should be noted that there is still significant debate about the distinction and the threshold between general and specialised palliative care [7, 11, 13]. Yet, appropriate differentiation between these patient groups is a pre-requisite for adequate delivery of palliative care [6, 14].

Identification of palliative care needs

The lack of consensus on clear and comprehensive criteria for identifying patients in need of palliative care makes it difficult for professionals who are not specifically trained in this area [8, 15]. This difficulty may be compounded by

other obstacles such as lack of knowledge or the feeling of being at a loss about when to talk about palliative care with patients and their families [2, 12]. In addition to raising awareness of palliative care among professionals during their training, the use of a specific instrument is recognised as helping to identify patients requiring palliative care [3, 16].

A number of instruments to identify patients in need of palliative care are available [17, 18, 19]. They are mostly screening checklists. They include a combination of different criteria related firstly to the severity and the progression of the disease (specific indicators) and secondly to the fragility generated by the disease (general indicators). Some instruments are dedicated only to specific populations or settings. Three instruments stand out as the most frequently used: the Gold Standards Framework Prognostic Indicator Guidance (GSF-PIG) [20], the Supportive and Palliative Care Indicators Tool (SPICT) [21] and the NECesidades PALiativas tool (NECPAL CCOMS-ICO) [22]. The few studies carried out with these instruments give encouraging signs of an improvement in the identification of patients in need of palliative care, but do not provide any evidence of early detection or widespread clinical use of these instruments. None of them makes the distinction between general and specialised palliative care needs [12, 17, 18, 19]. Most of the existing instruments do not provide recommendations for practice. Furthermore, the existing instruments have so far only been partially validated. Criterion validity, when assessed, was based on mortality prediction, which is incongruent with the concept of early integration of palliative care [23, 24, 25, 26, 27]. Currently, no instrument is yet widely recommended and used at international or national level.

Among the different existing instruments, the use of the “surprise question” (“Would you be surprised if this patient died in the next 12 months?” – an intuitive question that allows to estimate the prognosis), is not consensual [28, 29]. When present, it is sometimes a mandatory entry to continue the instrument, and the expected time to death is not always the same (mostly varying between 3–12 months). The surprise question has been tested many times. Depending on the time to expected death, its sensitivity ranges from 11.6% to 95.6% and its specificity from 13.8% to 98.2% [23, 30, 31, 32, 33]. This question is still controversial for non-oncological patients due to the unpredictability of their disease trajectories [30, 31]. Similarly, it does not allow to identify patients with a palliative situation at diagnosis and a life expectancy of more than one year, such as those with amyotrophic lateral sclerosis or glioblastoma. However, the surprise question is easy to use and to integrate into daily practice, and can thus help to improve the identification of patients in need of palliative care.

Abbreviations used in the article

ID-PALL IDentification of patients in need of PALLiative care

A new instrument to identify patients in need of palliative care

To fill in the gaps mentioned above, we developed ID-PALL (IDentification of patients in need of PALLiative care), a new screening instrument developed as a clinician-reported outcome measure [34]. The main stages of its validation have been completed [35]. ID-PALL does not require detailed medical information and can be used by physicians as well as nurses for all adult patients, regardless of their pathology and place of care or living. It has been designed to be as short as possible to facilitate its use.

ID-PALL is a two-part instrument (Figure 1). The first part, ID-PALL G, identifies patients in need of general palliative care using 7 items such as the “surprise question”, data related to frailty and vulnerability factors associated with a non-curable disease, cessation of curative treatments, aspects of psychosocial suffering or professionals' needs. The second part, ID-PALL S (8 items), allows the identification of patients requiring specialised palliative care, considering, for example, the complexity of assessing and treating symptoms, severe existential suffering, disagreement or uncertainty regarding the therapeutic project, or anticipated care plans that are difficult to implement. ID-PALL S should only be completed if ID-PALL G is positive. In both parts, the physical, psychological, and

existential dimensions of the person are considered, while taking into account the needs of relatives and professionals.

The criterion validity of ID-PALL was tested in two Swiss internal medicine departments. More than 2200 patients were assessed by nurses and primary care physicians using the instrument and by a medical-nursing pair specialised in palliative care, which was considered the *gold standard*. All assessments took place after two to four days of hospitalisation. The structural validity and internal consistency of the instrument were also measured [35].

The average age of the patients evaluated was 73 years (± 16.5). More than 70 % had non-oncological diseases, mainly heart failure, chronic obstructive pulmonary disease or dementia. A single checked ID-PALL item proved to be the best threshold to detect both the patients requiring general palliative care (ID-PALL G) and those requiring specialised palliative care (ID-PALL S). With a cut-off at 1, ID-PALL G has a sensitivity of 80 % and a specificity of 58 % while ID-PALL S has a sensitivity of 82 % and a specificity of 64 % [35].

A screening instrument aims at estimating the probability of needing palliative care. In this perspective, sensitivity (the likelihood that the instrument is positive when the patient is judged to have palliative care needs by the gold standard) was prioritized over specificity (the likelihood that the instrument is negative when the patient is judged

ID-PALL® G

Identification of patients in need of General PALLiative Care.

General palliative care is provided by professionals without specialised palliative care training in all care settings and contexts.

Please respond to all of the statements below relative to the patient's **current situation**:

1. Would you be surprised if this patient died in the next 12 months ?	<input type="checkbox"/> Yes <input type="checkbox"/> No
2. The patient has a progressive illness or group of illnesses or comorbidities that limits their life expectancy AND presents (select all that are applicable): a decline in general functioning (with limited reversibility and an increase in need for support in day to day activities) OR a pronounced instability over the last 6 months (defined by: one uncontrolled symptom from the patient's point of view OR a pressure ulcer category ≥3 OR more than one acute delirium episode, infection, unscheduled hospitalisation or fall) OR psychosocial or existential suffering (of the patient or people close to them) OR the need for support in making decisions during the final stages of life	<input type="checkbox"/> Yes <input type="checkbox"/> No
3. Current or planned interruption of treatments with curative intent or vital support measures (eg: artificial ventilation, dialysis, artificial feeding or hydration)	<input type="checkbox"/> Yes <input type="checkbox"/> No
4. Request for comfort care or palliative care from the patient, people close to them or health professionals	<input type="checkbox"/> Yes <input type="checkbox"/> No

If you have ticked **NO to question 1 OR YES to at least ONE of the statements 2, 3, or 4**, the patient is likely to require general palliative care. Please complete the ID-PALL S questionnaire on the next page and refer to the general palliative care practice recommendations.

ID-PALL® S

Identification of patients in need of Specialist PALLiative Care.

Specialised palliative care is provided by or with professionals specialized in palliative care.

Please respond to all of the statements below, relative to the patient's **current situation, only when the response to the ID-PALL G is positive**:

1. Presence of at least one severe and persistent symptom , including pain, that has not responded satisfactorily to treatment within 48 hours.	<input type="checkbox"/> Yes <input type="checkbox"/> No
2. Difficulties in evaluating physical symptoms or psychological, social difficulties or spiritual distress	<input type="checkbox"/> Yes <input type="checkbox"/> No
3. Disagreement or uncertainty on the part of the patient, people close to them or health professionals regarding, for example, medical treatments, resuscitation code or complex decisions	<input type="checkbox"/> Yes <input type="checkbox"/> No
4. The patient has severe psychosocial or existential suffering (eg: marked symptoms of anxiety or depression, feelings of isolation or of being a burden, loss of meaning or hope, desire to die, or has made a request for assisted suicide)	<input type="checkbox"/> Yes <input type="checkbox"/> No
5. People close to the patient experience severe psychosocial or existential suffering (eg: marked symptoms of anxiety or depression, major feelings of exhaustion, major disruption to the functioning of the family system, loss of meaning or hope)	<input type="checkbox"/> Yes <input type="checkbox"/> No
6. Palliative sedation is envisaged (to relieve an intolerable refractory symptom by decreasing the level of consciousness using specific medication)	<input type="checkbox"/> Yes <input type="checkbox"/> No
7. Advance care plan or advance directives are difficult to establish with the patient and/or people close to them	<input type="checkbox"/> Yes <input type="checkbox"/> No
8. In your opinion, the patient, people close to them or health professionals could benefit from the intervention of palliative care specialists .	<input type="checkbox"/> Yes <input type="checkbox"/> No

If you have ticked **YES to ONE of the above statements**, the patient is likely to require consultation of a specialist palliative care team.

ID-PALL® v1, 2020, F. Teike Lüthi et al.

Figure 1. ID-PALL (Use permitted after free registration on the website: www.chuv.ch/id-pall).

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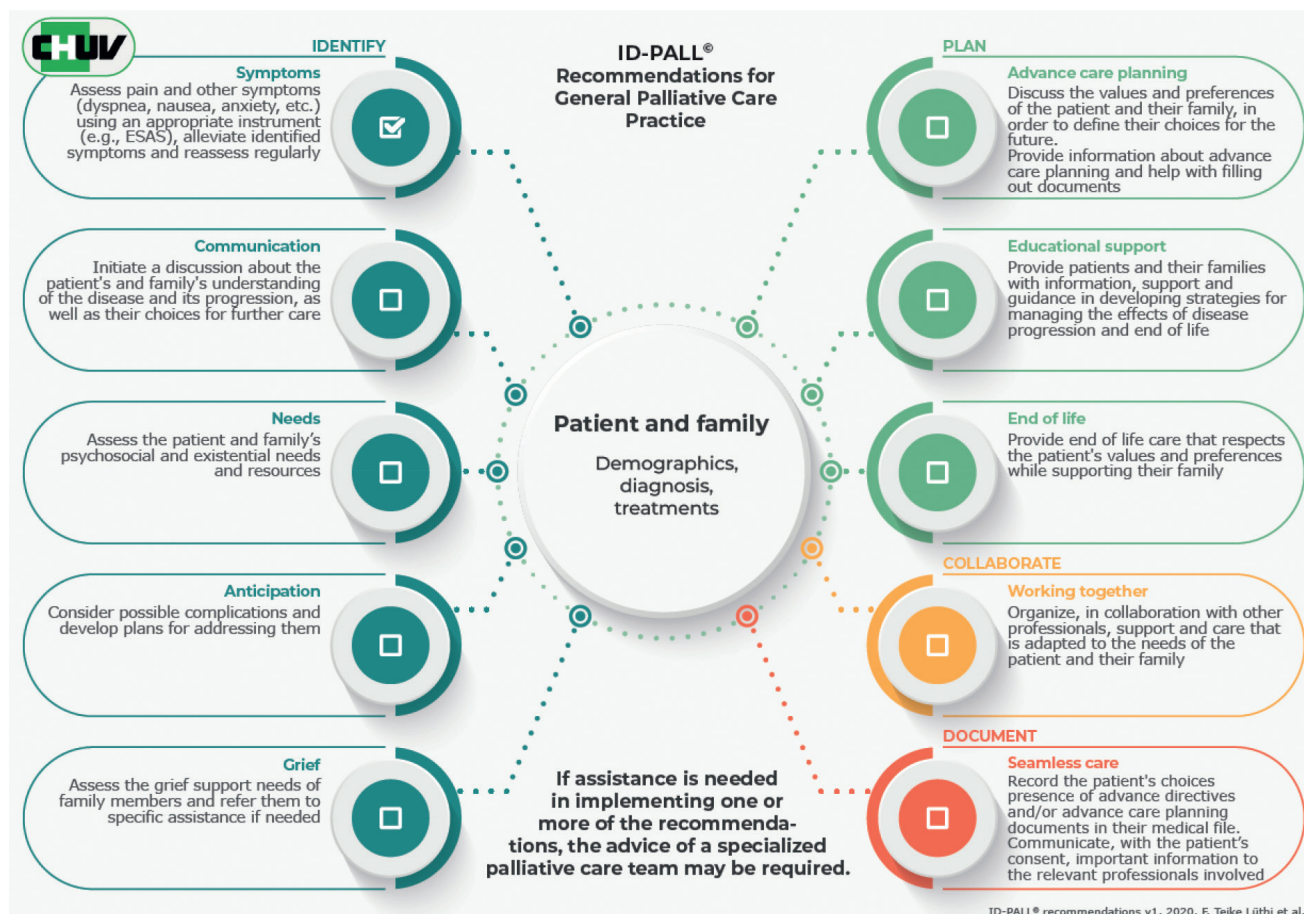


Figure 2. ID-PALL recommendations for general palliative care practice.

not to be in need of palliative care by the gold standard). Thus, “false negatives”, i.e. patients who are not identified as needing palliative care by the instrument although they be, should be minimised. This is more important than limiting the number of “false positives”, i.e. patients identified as needing palliative care by the instrument when they do not in fact need it. The priority lies in allowing for the early identification of as many patients as possible, while keeping in mind that this screening instrument should above all serve as a “red flag” for professionals, in order to discuss the care plan in detail before providing palliative care to the patient.

Recommendations for general palliative care practice

Identifying the need for palliative care only makes sense if recommendations for clinical practice can then be implemented. Thus, a literature review on good practice recommendations was carried out, followed by interviews and focus groups with future ID-PALL users, i.e. nurses and primary care physicians, as well as questionnaires addressed to palliative care specialists in Latin Switzerland. At the end of this process, a guideline with 10 recommen-

dations was developed (Figure 2). Recommendations are grouped into four categories: identification, planning, collaboration and documentation. We deliberately decided not to go into too much details in terms of operationalisation, so that each of these recommendations could be tailored to the specificity of the different clinical settings.

Thus, when ID-PALL G is positive, professionals can implement general palliative care independently of specialists. Nevertheless, in case of difficulties, they can refer to a specialist palliative care team for advice. When ID-PALL S is positive, it is recommended that palliative care specialists be contacted to initiate collaboration between generalists and specialists in order to improve the quality of care of the patient and their relatives.

Conclusion

ID-PALL is a new, short, easy-to-use palliative care needs identification instrument, developed for all care and living settings (except for emergency, intensive care and socio-educational settings), and validated in internal medicine. Validation in other care settings, including community settings, is planned. ID-PALL has been developed for inter-professional practice in order to encourage discussion around the therapeutic project, with the aim of improving

Key messages

Early identification of palliative care needs is a public health priority and a responsibility of all health professionals. The use of a validated instrument can facilitate this identification. ID-PALL is a new, short and easy-to-use instrument that allows the identification of palliative care needs with the distinction between general and specialised palliative care.

the care and thus the quality of life of patients and their relatives. ID-PALL, its instructions for use and the recommendations for the practice of general palliative care are available in French, German, Italian and English on the website of the Palliative and Supportive Care Service of the CHUV (www.chuv.ch/id-pall). Try them out to see if Peter and his relatives need palliative care!

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History

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Conflict of Interest

There are no conflicts of interest.

Dre Fabienne Teike Lüthi

CHUV, Centre hospitalier universitaire vaudois
Service de soins palliatifs et de support
NES/04/4020
Av. Pierre Decker 5
1011 Lausanne

Fabienne.Teike-luethi@chuv.ch