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## Research Paper

### Feasibility and validity of a tool for identification of people with intellectual disabilities in need of palliative care (PALLI)



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## ABSTRACT

**Background:** There is a need for a specific tool that supports healthcare professionals in timely identifying people with intellectual disabilities (ID) in need of palliative care. Therefore, we developed PALLI: a tool for screening deteriorating health, indicative of a limited life expectancy. **Aims:** We evaluated feasibility, construct validity and predictive validity of PALLI.

**Methods:** 190 people with ID likely to be in need of palliative care were included. Physicians and daily care professionals (DCPs) completed PALLI and provided information on health outcomes at baseline, after 5–6 months and after 10–12 months. Linear Mixed Models and Generalized Linear Mixed Models were used to test validity.

**Results:** Feasibility was adequate: physicians and DCPs were able to answer most items with ‘yes’ or ‘no’ and within a short amount of time. Construct validity was promising: a higher PALLI score at baseline was related to a higher level of decline in health, a higher symptom burden, a lower quality of life and more ADL-dependency at baseline. Predictive validity: only a higher physician-reported PALLI score at baseline significantly increased risk of death within 12 months.

**Conclusions:** PALLI shows promising feasibility and validity and has potential as a tool for timely identifying people with ID who may benefit from palliative care.

## What this paper adds?

This study showed the first promising results regarding feasibility, construct validity and predictive validity of a screening tool for deteriorating health, indicative for a limited life expectancy, in people with ID (PALLI). Based on these results we think that PALLI is useful for timely identification of people with ID who may benefit from palliative care and for facilitating discussion and creating

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consensus about (future) planning and provision of palliative care in this specific and more vulnerable population. This may help to attain the highest level of quality of end-of-life for people with ID.

## 1. Introduction

There is a growing interest in palliative care, “*an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness*” (WHO Definition of Palliative Care, 2002), for people with intellectual disabilities (ID), in research as well as in practice (Read, 2013; Stein, 2008; Tuffrey-Wijne, 2003; Tuffrey-Wijne, Curfs, & Deliens, 2016). Healthcare professionals in the care for people with ID are increasingly interested in timely identification of the people with ID who may benefit from palliative care, because it enables anticipatory care provision in which people’s needs and preferences are discussed early in the course of a serious illness. Furthermore, informed decisions about the planning and provision of palliative care can be made (Beernaert et al., 2015; Sawatzky et al., 2016; Tuffrey-Wijne, McLaughlin et al., 2016), such as about the best place to provide this palliative care (Bekkema et al., 2015). Timely identification of people in need of palliative care may help attain the highest level of quality of the end of life. Up to now, it seems that timely identification in people with ID is not a common or conscious practice. Therefore, in this study we evaluated feasibility, construct validity and predictive validity of a newly developed screening tool that was designed to help healthcare professionals identify people with ID in need for palliative care.

A recent Dutch study reported that for Intellectual Disability Physicians (ID-physicians) the identification of people with ID in need of palliative care is often a result from a process in which multiple signals provided by different information sources converge and lead to growing awareness (Vrijmoeth, Barten et al., 2016). Each individual process has unique features and its development can be complex and difficult because of the variety of factors involved: whether or not underlying diseases are identified, the stage and prognosis of the disease and the remaining treatment options, the quality of communication between physician and person with ID, familiarity with the person with ID, and how physicians value communication with proxies as providers of contextual information. Delays in and uncertainties about diagnosis of underlying diseases are common because of the communicational challenges, the a-specific presentation of problems and the reliance on proxies (Mastebroek et al., 2016; Read, 2013; van Schroyensteyn Lantman-de Valk & Walsh, 2008).

This calls for a specific tool that supports healthcare professionals in identifying people with ID who are in need for palliative care at the earliest stage possible. For the general population such tools have already been developed (Maas, Murray, Engels, & Campbell, 2013), such as the GSF Prognostic Identification Guidance (Thomas & Armstrong Wilson, 2016), the Supportive and Palliative Care Indicators Tool (SPICt; Boyd & Murray, 2010), and the Radboud Indicators for Palliative Care Needs (RADPAC; Thoosen et al., 2012) or the Necesidades Paliativas Centro Colaborador de la Organización Mundial de la Salud – Institut Català d’Oncologia tool (NECPAL CCOMS-ICO Tool; Gómez-Batiste et al., 2016). These tools are valuable, however, we anticipate that they often may not be applicable to people with ID. This is because in people with ID diseases may be diagnosed late or not diagnosed at all, while these tools rely on clinical indicators categorised for different diseases (e.g., cancer, dementia, organ failure). Furthermore, the included general indicators of decline in these tools are not specific to people with ID and may not be the norm for people with ID due to an early onset of frailty (Schoufour, Mitnitski, Rockwood, Evenhuis & Echteld, 2013), a high risk of multimorbidity (Hermans & Evenhuis, 2014; McCarron et al., 2013), and because of the a-specific presentation of problems and communicational challenges in caring for people with ID.

Therefore, we developed PALLI (PALliative care: Learning to Identify in people with ID): a tool that can be used to screen people with ID for deteriorating health indicative of a limited life expectancy (Christians et al., 2016). It provides a quick overview of the current health status compared to a previous period of three to six months. With this tool, healthcare professionals should be able to identify people with ID in need of palliative care provision. PALLI was developed using a consensus approach, based on data from healthcare professionals in a survey (Vrijmoeth, Christians et al., 2016), interviews (Vrijmoeth, Barten et al., 2016) and focus groups. Compared to other tools, like SPICt and RADPAC, PALLI is less diagnosis-driven and focuses more on relevant changes in characteristic behaviour, daily functioning and symptoms indicative of deteriorating health. It combines items on changes in day-to-day experiences specific for people with ID and items on more overarching medical knowledge, which makes it possible for not only physicians, but also for daily care professionals (DCPs, see Box 1) to complete PALLI. These DCPs are important sources of information (Mastebroek et al., 2016; Vrijmoeth, Barten et al., 2016).

For the work we present here, physicians and DCPs completed PALLI for a selected group of people with ID in a prospective follow-up study. Our first aim was to explore the feasibility of PALLI for use by both professionals by means of exploring ability to provide an answer of ‘yes’ or ‘no’, number of items not known, total PALLI score and time needed for completion. Secondly, we aimed to explore the construct validity of PALLI by means of the association with outcomes related to deteriorating health, i.e. overall decline, symptom burden, illness burden, quality of life (QoL), and dependency in activities of daily living (ADL). Thirdly, we aimed to explore the predictive validity of PALLI by means of the association with these outcomes at follow-up and with death within 12 months.

## 2. Methods

### 2.1. Sample and procedure

Between May and November 2014 we requested 9 organizations, throughout the Netherlands in both rural and urban areas, that provide care to people with ID in the Netherlands to select and include eligible people for our study. We used a convenience sample;

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