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## End-of-Life Care and the Use of an Integrated Care Pathway

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## End-of-Life Care and the Use of an Integrated Care Pathway

### Abstract

Liverpool Care Pathway is an integrated care pathway (ICP) designed to ensure the provision of high-quality end-of-life care. However, the ICP has come under substantial criticism, suggesting that its use is related to poor care. This study explores nurses' use of the ICP to dying patients in Norwegian nursing homes. We conducted a qualitative study using an abductive, mystery-focused method to analyze the experiences of 12 registered nurses. Our findings show that the nurses experienced the ICP as a very useful tool in end-of-life care, although they were actually working independently of the ICP in the provision of ongoing bedside care for the dying patients. This can be understood as following: (I) the ICP is not compatible with the complex problems of dying patients; therefore, nurses must tinker with the ICP in order to give dying patients proper and dignified care; (II) the ICP is a myth with symbolic power, legitimizing care makes nurses positive towards the ICP; and (III) using the ICP as a loosely coupled system creates novel effects on nursing practice. In this study, we have shown how the ICP creates a common culture through a process of individual and collective sensemaking, which we labelled clinical mindlines.

### Keywords

Integrated Care Pathway, Liverpool Care Pathway, End-of-Life Care, Reflexive and Creative Methodology, Mystery as Method, Abductive Reasoning

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## End-of-Life Care and the Use of an Integrated Care Pathway

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*Liverpool Care Pathway is an integrated care pathway (ICP) designed to ensure the provision of high-quality end-of-life care. However, the ICP has come under substantial criticism, suggesting that its use is related to poor care. This study explores nurses' use of the ICP to dying patients in Norwegian nursing homes. We conducted a qualitative study using an abductive, mystery-focused method to analyze the experiences of 12 registered nurses. Our findings show that the nurses experienced the ICP as a very useful tool in end-of-life care, although they were actually working independently of the ICP in the provision of ongoing bedside care for the dying patients. This can be understood as following: (I) the ICP is not compatible with the complex problems of dying patients; therefore, nurses must tinker with the ICP in order to give dying patients proper and dignified care; (II) the ICP is a myth with symbolic power, legitimizing care makes nurses positive towards the ICP; and (III) using the ICP as a loosely coupled system creates novel effects on nursing practice. In this study, we have shown how the ICP creates a common culture through a process of individual and collective sensemaking, which we labelled clinical mindlines. Keywords: Integrated Care Pathway, Liverpool Care Pathway, End-of-Life Care, Reflexive and Creative Methodology, Mystery as Method, Abductive Reasoning*

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The Liverpool Care Pathway is an integrated care pathway (ICP)<sup>1</sup> developed in the United Kingdom (UK) in the 1990s for use in the hospice setting to ensure the highest quality of care during the last days and hours of life (Ellershaw & Wilkinson, 2011). It has since been adopted for use in other care settings, such as hospitals, home care services, and nursing homes. The ICP can be described as an assessment and treatment planning tool which aim is to provide high-quality, tailored care to patients based on their individual holistic needs as they approach their inevitable deaths (Ellershaw, Foster, Murphy, Shea, & Overill, 1997).

The ICP is currently in use in at least 17 countries worldwide (Husebø, Flo, & Engedal, 2017). In Norway, approximately 454 institutions are registered as ICP users; moreover, one-third of all nursing homes have adopted the ICP for use in end-of-life care ( $n = 329$ ) (KLB, 2019). The Norwegian version is based upon the 11<sup>th</sup> version of the ICP; it is available both as a paper version and electronically. It consists of three parts, the first of which provides an initial assessment of the patient's condition including a plan for further treatment and care. The second part consists of an ongoing assessment of the plan of care and the last part contains an assessment after death has occurred (Ellershaw & Wilkinson, 2011).

Despite the promise of high-quality care, there has been considerable criticism of the use of the ICP, claiming that it has been used as a *tick-box* exercise without any genuine care for the patients or their relatives (Neuberger et al., 2013). Concerns have also been raised about the possibility that the tool has contributed to the shortening of some patients' lives (Høeg,

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<sup>1</sup> There is no consensus about the name of the ICP. In Norway, the ICP was first called Liverpool Care Pathway (LCP), but changed the name to *Livets siste dag* – plan for lindring i livets slutfase (translated: *End-of-life care – Plan for caring during the last days of life*) in 2015 after a minor revision. Because of this, we have chosen to use the generic name ICP when referring to LCP.

2015; Johansen & Nave, 2016; Neuberger et al., 2013), and that it is used to cover up a lack of staff competence (Husebø et al., 2017; Neuberger et al., 2013; Nilsen, 2015).

In the UK, these criticisms led to the launching of the Neuberger independent review of the ICP (Neuberger et al., 2013). The subsequent report—*More Care, Less Pathway*—revealed poor care related to the use of the ICP in acute hospitals, especially in cases where the tool had been poorly implemented (Neuberger et al., 2013). Based on these results, the review panel issued a recommendation against the use of the ICP, arguing that it should be replaced with an end-of-life care plan for individual patients (Neuberger et al., 2013). The UK government subsequently opted for a national ICP phase-out over the course of 6–12 months. Notwithstanding, no other country using the ICP has chosen to withdraw the instrument from use.

Despite this, the ICP is still plagued with criticism. One accusation is that the ICP cannot be called an evidence-based procedure because it lacks robust evidence. For example, there are few RCTs or other well-designed controlled studies with which to attest to the efficacy of the ICP (Husebø et al., 2017). It is claimed that there is an urgent need for well-designed, robust studies before justifying the continued rollout of the ICP (Chan, Webster, & Bowers, 2016; Chan, Webster, Phillips, & Currow, 2014; Currow & Abernethy, 2013; Hughes, Preston, & Payne, 2013; Husebø et al., 2017; Meneses-Echàvez, Flodgren, & Berg, 2016; Sleeman, 2013).

Notwithstanding, these criticisms are subject to an underlying assumption that only empirical studies relying on rigorous or robust methodologies constitute valid forms of knowledge. So-called *soft evidence* is downplayed as invalid knowledge, relying on weak study designs and methods. This becomes evident in regard to the wealth of *soft evidence* that exists but is ignored when summarizing the evidence for ICP. For example, several studies (both qualitative and quantitative) exist that show positive outcomes in relation to the use of the ICP both in *secondary* (Costantini, Pellergrini, et al., 2014; Costantini, Romoli, et al., 2014; Di Leo, Beccaro, Finelli, Borreani, & Costantini, 2011; Gambles, Stirzaker, Jack, & Ellershaw, 2006; Veerbeek, van Zuylen, et al., 2008), and *primary* care (Andersson, Lindqvist, Fürst, & Brännström, 2018a, 2018b; Brattgjerd & Olsen, 2016; Brännström, Fürst, Tishelman, Petzold, & Lindqvist, 2016; Clark, Marshall, Sheward, & Allan, 2012; Collins, Hughes, Ibbotson, Foy, & Brooks, 2016; Ekeström, Olsson, Runesdotter, & Fürst, 2014; Lemos Dekker, Gysels, & Van der Steen, 2017; Veerbeek, Van der Heide, et al., 2008; Veerbeek, van Zuylen, et al., 2008; Watson, Hockley, & Murray, 2010). To our knowledge there are no studies emphasizing general poor care in relation to the use of ICP.

However, previous ICP studies are biased toward evaluation studies that aim to compile surface level empirical data. Such designs, however, inevitably lead to the reproduction of existing wisdom, and fail to challenge underlying assumptions (Alvesson, Gabriel, & Paulsen, 2017; Alvesson & Sandberg, 2013). This undermines the fact that knowing is not just (or primarily) about passively *representing* the world, but about *intervening* in it (Brinkmann, 2014; Hacking, 1983). In line with Alvesson and Sköldberg (2018), interesting knowledge is constructed when investigating the deep structures of the empirical material through the use of abductive reasoning. Abductive reasoning is the idea that when something unexpected appears on the empirical level, thus signifying a breakdown in our typical understanding of a phenomena, a reflexive and creative dialogue should take place between the event and the different theoretical assumptions at the surface level; the outcomes of which should stimulate the development of new creative in-depth ideas about a research phenomenon (Alvesson & Kärreman, 2011).

To our knowledge, no previous ICP study has yet investigated the deep structures of the empirical material. The overall purpose of this study, therefore, is to use abductive

reasoning in the hope of developing in-depth knowledge about nursing practices in relation to the use of the ICP with dying patients in Norwegian nursing homes.

We chose to limit the study to investigate the use of the ICP in nursing homes because the accusations of poor care related to the Norwegian ICP are specifically related to this context (Husebø et al., 2017; Høeg, 2015; Johansen & Nave, 2016; Nilsen, 2015). We also limited the study to the investigation of the nursing practices in relation to the use of the ICP because nurses have overall responsibility for the continuous care of dying patients. Finally, the study was limited to the investigation of the following question: “What is occurring in nursing practice when using the ICP, and why is this happening?”

### About the Authors

The first author (MB) is enrolled as a Ph.D. Candidate at Nord University's program for Ph.D. in Professional Praxis under the supervision of the second (RMO, Ph.D.) and third author (IJD, Ph.D.) of this study. In her Ph.D. project, MB is exploring the influence of standardization on the nursing practice. Standardization was chosen as a concept because its use has expanded rapidly within the past decades without knowing the real consequences of implementing this idea into practice. In addition to being researchers, all authors are registered nurses and have experience with end-of-life care. MB and RMO have mainly been working within the context of community health care and geriatrics. IJD has been working in pediatric wards within a university hospital.

### Method

#### Study Design

We conducted a qualitative study using a reflexive and creative methodology developed by Alvesson and Sköldbberg (2018), which aim is to transcend the empirical level and to use reflexive and creative imagination to explore the deep structures lying beyond the empirical material (data). We believe this will inspire to a deeper knowledge rather than just compiling surface data, which most often lead to a reproduction of existing wisdom.

Ontologically we assume the existence of a reality beyond the researcher. As researchers, we are capable of giving insightful information about this world. Nevertheless, how humans regard *the world* is affected by our cultural and social context; therefore, the empirical material must be seen as socially constructed<sup>2</sup>, where language constructs rather than mirrors phenomena (Alvesson & Kärreman, 2011). Which means that our knowledge of the phenomenon will always be limited in the sense that we are not guaranteed mirroring the world accurately. However, as human beings, we have the ability to achieve an insightful *understanding*<sup>3</sup> of the world by drawing inferences between particulars and universals, which is a necessary prerequisite for maneuvering in the world. We believe this ability is also beneficial within the scientific method and paradigm. That is, by using the empirical material as a starting point (induction) where particulars are carefully examined through an interplay with universals/theoretical assumptions (deduction), we are able to give meaning to phenomena which transcend the empirical level (abduction).

When using the reflexive and creative methodology, we are taking advantage of this ability by seeing the empirical material as a source of inspiration and as a partner for critical

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<sup>2</sup> Data are affected by the theory-impregnated interpretation from both the research objects and the researchers. Because of this fusion of theory and data, we will be using the term “empirical material” synonymous with the word “data” to highlight the constructed nature of the data.

<sup>3</sup> Meaning a form of knowledge, which is *standing under* the phenomena, not mirroring the phenomena.

dialogue. Rather than assuming that “data” point in a specific direction, we explore whether the empirical material can encourage the challenging and rethinking of established wisdom (Alvesson & Kärreman, 2011). That is, we are using different theoretical perspectives (across disciplines) as a source in the critical dialogue to challenge the underlying assumptions of our worldview, hence giving rise to a new insight about the world. Transferred to this study, this means that when using this methodology we are able to transcend the empirical level through the challenging of underlying assumptions, thereby gaining valuable in-depth knowledge about the use of the ICP to dying patients.

### Participants and Setting

Twelve registered nurses (RNs) working at eight nursing homes across Norway consented to participate in this study. The nursing homes were located in two different counties. All nurses worked at least 80% of a full position. Table 1 provides an overview of the participants. Pseudonyms are used to hide the identity of the nurses.

Table 1.

#### *Participant Characteristics*

RN	Advanced Education	Nursing Home Ward	Years of Experience	Municipality
Sarah	-	Long-Term Ward	14	A
Mary	-	Long-Term Ward	15	A
Hannah	Palliative Nursing	Palliative Ward	4	A
Wiona	Palliative Nursing	Palliative Ward	22	A
Anette	Intensive Nursing	Short-Term Ward	30	B
Heidi	-	Short-Term Ward	19	B
Tammy	-	Long-Term Ward	12	C
Karen	Palliative Nursing	Short-Term Ward	14	D
Vera	-	Short-Term Ward	1	D
Lilly	-	Long Term Ward	3	C
Jenny	-	Short-Term Ward	5	C
Laura	-	Short-Term Ward	16	C

We received help with recruiting nurses for this study through a Competence Center, located in western Norway, responsible for the implementation and use of the ICP. The nurses received an email invitation to the study, along with information about the study. All nurses invited also chose to participate in the study.

### Data Collection

During the spring of 2018, we conducted individual interviews with the nurses at their workplace. The interviews were carried out by the first author. In using a reflexive and creative research methodology, it is to make inquiries fairly open when conducting interviews (Alvesson & Kärreman, 2011). As such, we chose to use an in-depth, open-ended interview guide to gain knowledge about nursing practice in relation to the use of the ICP (Table 2). Additional information regarding the nurses' gender, age, education, number of years working with the ICP, and years working in their present nursing home ward was collected before the audio recording, along with information about the ward itself.

Table 2.

*Interview Guide*


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What is your general experience with the use of the ICP?
✓ What does it mean that...
✓ Why is it so...
✓ What do you feel/think when...

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Can you tell me about the last time you used the ICP for a dying patient at your ward?
✓ What does it mean that...
✓ Why did you do this...
✓ What did you feel/think/do when...
Are there other events/situations you can tell me about in which you used the ICP?
✓ What does it mean that...
✓ Why did you do this...
✓ What did you feel/think/do when...

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The interviews lasted approximately 45–90 minutes, and were audio recorded and transcribed verbatim by the first author.

### **Ethical Considerations**

The study was conducted in accordance with the *Declaration of Helsinki* (WMA, 1964/2013), and is approved by the Norwegian Centre for Research Data (Number: 59346). All participants received written and oral information about the study, and all participants voluntarily consented to participation. All data has been anonymized, and the identity of the participants cannot be recognized. Audio recordings and transcripts are available only for the researchers in this study.

### **Data Analysis**

We used a reflexive and creative method—*mystery as method*—in the analysis of the interview transcripts. This is a mystery-focused method using abductive reasoning to transcend the constraints of empirical data (Alvesson & Kärreman, 2011). The idea is that when something unexpected appears on the empirical level, thus signifying a breakdown in our typical understanding of a phenomena, a reflexive and creative dialogue should take place between the event and the different theoretical assumptions at the surface level; the outcomes of which should stimulate the development of new creative in-depth ideas about the research phenomenon (Alvesson & Kärreman, 2011).

Our aim in embracing this method of inquiry is to explore whether constructing and solving mysteries could challenge existing assumptions and stimulate new creative ideas about the research phenomenon (Alvesson & Kärreman, 2011). Alvesson and Kärreman (2011) have developed a five-phase analysis process<sup>4</sup> within their method. However, they warn researchers that their method should be used only as a blueprint. As such, they advocate for a flexible approach in which the researcher is free to adapt and to customize the model to suit the needs of their specific project and local circumstances. In this regard, we chose to analyze the interview data using a modified version of Alvesson and Kärreman's five phases of analysis:

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<sup>4</sup> What is unique within this analysis method is the discussion section is incorporated within the last two phases of the analysis. We have therefore merged the results- and discussion section within this paper.

- familiarization with the narrative of the empirical material,
- encountering breakdowns in understanding,
- constructing mystery,
- solving the mystery, and
- developing a solution to the mystery.

**Familiarization with the narrative of the empirical material.** The key element in this phase was to develop familiarity with the narrative of the empirical material. In this regard, all authors were involved in an inductive reading of the interviews. Our desire was to be open to the experiences of nurses in using the ICP in end-of-life care. Instead of searching for patterns and categories, we tried to let the empirical material speak for itself by making inquiries about the themes in a fairly open way (Alvesson & Kärreman, 2011). Rather than focusing on narrow themes (e.g., observation, documentation, caring, etc.), we asked ourselves, “What is going on here?” or “What is the empirical material actually telling us about nursing practice?”

**Encountering breakdowns in understanding.** The unanticipated – the things that do not fit into the existing worldview - is within this method seen as the gateway to reach depth beyond the empirical level. As such, the aim was to strive for achieving any breakdowns in understanding. In doing so, the first author began a search for patterns and deviations from the existing patterns (e.g., incoherencies, paradoxes, ambiguities, etc.). Alvesson and Kärreman (2011) highlight the importance of this (de)fragmentation process as it prevents the researcher from prematurely categorizing the phenomenon.

Another important element in reaching any breakdowns in understanding was to avoid seeing the social world (interview text) as self-evident and familiar. As such, the mission was to alienate from the world (i.e., nursing practice) in order to get behind taken-for-granted assumptions. One way of doing this is to problematize existing wisdom (Alvesson & Kärreman, 2011). That is, instead of thinking *with* established concepts, the task was to problematize and challenge underlying assumptions by *deconstructing* and *rethinking* about established concepts. One example of a question that constantly appeared in relation to this was, “The nurses are talking about *using* the ICP – but what does it actually mean *to use*?”

While the first author was processing *all* these different analytical steps, a discrepancy in the nursing practice emerged that could not be explained by previous ICP studies. That is, at first glance, the ICP seemed to provide for a more proper and dignified end-of-life; however, after delving more deeply into the empirical material, it appeared that the nurses were not actually using the ICP as it was intended. This unexpected experience can be described as “a breakdown in understanding.”

**Constructing mystery.** The next phase was to formulate a preliminary interpretation of the breakdown from the previous phase. Alvesson and Kärreman (2011) describe this as the formulation of a mystery. The first author used the information from the previous phase to develop a description of the unexpected paradox within the study, where quotes from the nurses were used to substantiate the descriptions of the mystery.

In order to avoid making unsupported interpretations based on the empirical material, the first author requested the involvement of the co-authors to validate the formulation of the mystery (i.e., internal validation). After reading through the description of the mystery and the quotes associated with it, the co-authors came with suggestions of some small linguistic changes in the formulation of the mystery and also suggestions of incorporating a few more quotes.

We finally agreed to present the mystery as a two-fold paradox, which is presented as the results of the first part of our research question (i.e., “What is occurring in nursing practice



when using the ICP?”): (I) nurses experience the ICP as a useful tool in end-of-life care, and (II) nurses are working independently of the ICP in the provision of bedside care to the patient.

**Solving the mystery.** In this fourth phase of analysis, the mission was to create possible solution(s) to the mystery (Alvesson & Kärreman, 2011). That is, “Why are the nurses experiencing the ICP as a useful tool when they are actually working independently of the ICP in the bedside care of the patients?” Also here, the first author had the responsibility in constructing preliminary solutions of the mystery. The task was here to be open to multiple interpretations and not letting taken-for-granted assumptions determine the solutions of the mystery. To accomplish this, she read a variety of literature from different disciplines and used this knowledge as a resource in the critical dialogue with the interview text. An (critical) interplay between particulars (facts from the data) and universals (different theoretical perspectives) took place, and this was in “back-and-forth process” in the purpose of achieving a deeper understanding of the mystery. The coauthors also played an active role in this phase of the research, thus strengthening the preliminary interpretations (i.e., internal validation).

Finally, all of the authors agreed on a three-fold solution to the mystery<sup>5</sup>: (I) the ICP is not compatible with complex problems, (II) the ICP is a myth with symbolic power, and (III) the ICP creates a novel effect on nursing practice. Each entity of the solution provides essential knowledge in understanding pieces of the mystery. Put together; they are giving in-depth knowledge of the second part of the research question (i.e., “Why is this happening?”).

**Developing the solution to the mystery.** In this final phase of analysis, our task was to go a step further in order to develop *theoretical contributions* to the body of knowledge based upon the results of the previous phase. This means undertaking a more systematic consideration of concepts and the relationships between these concepts (Alvesson & Kärreman, 2011), thus leading to a deeper understanding of the research phenomenon (i.e., internal validation), which also has broader relevance outside the scope of this study (i.e., external validation). In this theory development phase, all of the authors worked together (read and commented on each other’s contributions) to validate and evaluate the theoretical contributions of the study, while simultaneously stressing the strengths and limitations of these theoretical contributions.

## Results and Discussion

Over the course of the next three sections of this paper, we present the results of our study as *Mystery incarnated*, *Towards a solution of the mystery* and *Developing the solution of the mystery*. In the first section, *Mystery incarnated*, we give a description of the mystery and answer the first part of the research question: “What is occurring in nursing practice when using the ICP?” In the next section, *Towards a solution of the mystery*, we will discuss possible solutions of the second part of the research question: “Why is this happening?” Finally, in the last section, *Developing the solution of the mystery*, we summarize and conceptualize the main results of the study, showing how the findings may have broader relevance outside the scope of this study.

### Mystery Incarnated

Within this section we give a description of our findings as a two-fold mystery: (I) nurses experience the ICP as a useful tool in end-of-life care, and (II) nurses are working independently of the ICP in the provision of bedside care to the patient.

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<sup>5</sup> It is important for us to emphasize that we do not see this as “the only truth”. Taken another perspective (reading different literature) could have led to different solutions. However, we believe our findings are giving important insight into *possible solutions* of the mystery.

### ***I. Nurses Experience the ICP as a Useful Tool in End-of-Life Care***

When the nurses were asked to describe their own experience and practice with the ICP, each described the ICP as a useful tool in end-of-life care. They spoke about a change in practice towards more proper and dignified care for dying patients and their relatives. They claimed that the patients were being taken care of in a more holistic way after the introduction of the ICP, which offered them a *system* to follow, starting from the commencement of the dying phase to the actual occurrence of death. In the following analysis, we describe what is occurring within this process.

According to the nurses we interviewed, all health workers (i.e., not only the RN) who work at the bedside have become more alert to changes in the patient's situation after the introduction of the ICP. These changes were most apparent in the long- and short-term wards, but also on the palliative wards. For example, they described health workers as having become more alert to recognize when a patient is dying (which is a prerequisite of starting the ICP) after the introduction of the ICP. One reason for this may be that nobody wished to erroneously commence a patient on the ICP. Therefore, they became more aware of clinical changes that might otherwise suggest that the patient was approaching their end of life. Two participants went on record to state:

...I think we have become more alert...A prerequisite in starting the ICP is to identify the patient as dying, and I think this has led us to be more observant and aware of any changes...Should we put the patient on the ICP or not? Are there any signs or symptoms?...There is not always consensus about this subject, so we have to discuss it... "No, maybe we should wait and see..." or "Yes, we all agree that the patient has entered the dying phase"... (Mary)

...Before putting the patient on the ICP...It's a big responsibility...I mean, it is we [health workers working at the bedside] who often see the first signs...He may be more tired...He is more bedridden, showing less interest in eating and drinking... trouble with swallowing tablets, etc....It is we, not the doctors, who are at the patient's bedside... throughout the day,...who know the patients... That is one of the benefits of working in a nursing home...we are very familiar with the patients...Then any changes in the patient's condition will be reported to me or another nurse... If I have the responsibility, I will then go into the patient's room, assess their condition myself...and report to the doctor... We also did this before the ICP, but I think the whole concept...all that comes with it...it has led us to be more aware of any changes in the patient's condition... (Jenny)

Despite a patient being assessed as dying and having been put on the ICP, all of the nurses emphasized the need for on-going assessment in case the patient's condition were to improve, thus requiring withdrawal of the ICP. This would suggest that the nurses are not using the ICP as a *pathway to death*, thus shortening of the patient's life, but that they are acutely alert to changes in the patient's condition, including the possibility of improvement. Two nurses emphasized that while it was undesirable, erroneously putting a patient on the ICP resulted in no physical harm coming to the patient.

...We always consider...especially in patients with dementia...We had this elderly woman...She was bedridden, sleeping more or less throughout the day...When we offered her food and fluids, she refused to open her mouth... We

kept on moistening her mouth ... Everyone thought she was dying... But in the next moment, she was suddenly more awake, giving signs of wanting to eat and drink... I think she was put on and off the ICP three times... It's always difficult to know exactly... So we always have to consider whether we should continue or not... (Tammy)

... In fact, we are observing patients more frequently when they are put on the ICP... Then we are also more alert to changes which may assume an improvement... So, if we have to withdraw the ICP, it hasn't caused any harm to the patient... On the contrary, we have done everything in our power to give the patient proper care... (Heidi)

After deciding to start a patient on the ICP, a doctor and a nurse have the responsibility of completing the first part of the ICP. All of the nurses seem to find this part of the ICP very useful because it clarifies the responsibilities of the doctor, and simultaneously affirms a shift in the care of the patient from curative to palliative care. In other words, the ICP heralds the introduction of a new set of common goals in the care of the dying patient: To avoid inappropriate treatment and care, focus on alleviating pain and discomfort, and to give/create quality of life over the remaining days of life. This also includes taking care of the relatives of the patient. The ICP, therefore, is used to set the order of priorities in the care of the dying patient, helping nurses to plan, and thus be more prepared for changes in the patient's situation. Two of the participants in this study explained it thusly:

... It's so good! I mean, there is a plan to follow! We are now agreeing that we are not checking blood pressure, saturation, taking blood tests, giving antibiotics, you know... And the prescribing of the medications—it's so good! The doctor is also very fond of it! Everything is well-planned... Now we do not need to call after-hours primary health care... And the relatives are also more involved... You now have to *check out* that they have been informed... So, we all... the relatives included... agree that... "now, the patient is dying"... (Heidi)

... I find the plan very useful... it helps us speak the same language when caring for the dying... Looking for the same things... having focus on covering the same basic needs of the patients... Before the introduction of the ICP... I think it was more chaotic... There was no consensus on what to do... There was always someone who wouldn't realize that the patient was dying... Then it was much more focus on curative treatment... Now we have more focus on palliative treatment, on communication processes and the mental needs... (Karen)

The second part of the ICP was the subject highlighted the most by the nurses. This part of the ICP was described as the most commonly used part of the ICP because it deals with the ongoing assessment of the patient and is in continuous use until the patient's death. Participants described that this as a valuable checklist for ensuring that the holistic needs of the patient were being addressed. They also claimed that this part of the ICP helped to ensure that all nurses made the same observations and assessments of the patient's condition, thereby providing a standardized procedure and leaving nothing to chance:

... You have to go through all the points, and check off the boxes... Does the patient have pain? Is he nauseous? Is the mouth moist and clean? And so on... If

the answer is *no*, you should find a solution to relieve the discomfort or the pain... Maybe the patient needs some medication...Or maybe he just needs to change position in the bed...Or just holding the hands, comforting. So I think it functions as a good reminder for all of us! ... (Laura)

...I find this plan very useful...You have to observe all the points in the plan...You have to observe how the patient is breathing...Is he restless and so on...Before it was like this: Okay, you observe the patient...But what are we actually observing?...So I think it is a very useful tool for me... A safety net...Then I can check myself against it (the plan)... (Wiona)

Thus far, the empirical material has told a story about a standardized instrument that makes a positive contribution to dignified and proper end-of-life care. This finding is consistent with previous ICP studies. However, when looking more deeply into the empirical material, the story seems to be contradictory in some areas; that is, there appears to be a discrepancy between what is explicitly said and what emerges when the stories from nursing practice are fully revealed. Below we describe some of the discrepancies that emerged from this data.

## ***II. Nurses Are Working Independently of the ICP in the Ongoing Bedside Care of Patients***

A number of touching stories emerged in relation to the last days of patients' lives when we asked the nurses to describe incidents from their practice when using the ICP. The empirical material painted a picture of nurses who wished to do everything they could to give the patient a dignified and peaceful death. However, when the stories of the nurses were fully explored, it became evident that the nurses were acting independent of the ICP in the care of the dying patient. In other words, the nurses used the ICP as a reporting and documentation tool, not as an instrument for guiding their ongoing bedside care of the dying patients.

In fact, each of the nursing stories revealed that the participants mostly used the ICP at the beginning and at the end of their shifts. At the beginning of the shift, they used it to get information and an overview of the situation of the patient. At the end of the shift, they used the ICP to report on the patient's situation and to document the interventions they had implemented during the shift. The nurses told stories about having used sticky notes as temporary forms of documentation during the shift, with the documentation transferred to the electronic or paper-based ICP at the end of the shift.

...When I enter the patient room, I am not thinking of the ICP...I mean...How am I to explain it...I believe the points and the content of the ICP are in our head in a way...I do not have the ICP with me in the room...When I enter the room, I am focused on assessing the patient with a holistic gaze...I am sensitive to what the patient expresses...The non-verbal language... "Does he have a wrinkle in the forehead?... "Is he restless, and so on..." And then...the points in the ICP in a way...they appear or pop up within the assessment of the patient...[laughter]. For example...if he has pain, I have to find some painkillers...then I document this on a note, which is a reminder that I have to transfer the text to the ICP later... (Sarah)

...I don't have the ICP with me in the patient's room...I know the contents of the plan...what to look for...It has become automated in a way...But it is not in a way where I follow the plan rigorously or instrumentally...That is, I am not

looking for pain...nausea and so on...as it is described in the ICP...I think I am doing much of the same as I have always done...observation and things like that... (Hannah)

Some of the nurses may, however, take a quick overview of the checklist in part two of the ICP before entering the patient's room in order to remind themselves about what is important to observe and to do. Nevertheless, it appears that these same nurses were also acting independent of the ICP when caring for their dying patients. Vera, a newly graduated nurse, was one of the nurses who reported taking a quick glance at the ICP, as did Anette, an intensive care nurse who began working at the nursing home not long ago and had little experience with end-of-life care prior to having commenced working in the ward. This may indicate that nurses are somewhat more dependent upon the plan when they feel that they lack experience with end-of-life care. However, when delving into the story of Vera and Anette, it appears that they also operated independently of the plan after entering the patients' room. Both told stories about using their senses when encountering the dying patient:

...I did a quick look over the ICP before I entered the room... Then I went to the (patient's) bed...presenting myself, and at the same time taking a quick overview...looking at the face of the patient and also listening...“Are there any signs of pain or discomfort?”...and then gently touching the patient's hand or forehead... “Is the skin warm or cold, is it dry or clammy?” ...I have to be alert, listening...seeing...feeling...In this case, he (the patient) was stable. But this is what I always do... (Vera)

...The first thing I saw when entering the room was that she seemed to be a bit restless. I don't remember all of it, but I think I was starting an inner conversation with myself, and at the same time using all my senses... “Does she have pain?”... “Is she nauseous? How about breathing?”... “Is she lying in a bad position?”... “What about the skin?”... So I have to be fully present in the situation. I can't think of Mr. Hansen in the room next door. I can't think of everything I have left to do...I have to be vigilant to what the patient is trying to tell me... (Anette)

What becomes evident in this regard is that when nurses are working independently of the ICP in the provision of bedside care to their patients, they are not using the ICP instrumentally or as a tick box exercise. On the contrary, it turns out that the nurses were working in much in the same way as before the introduction of the ICP. The difference was, however, that the content of the ICP had been integrated as a part of the total knowledge base of the nurses, allowing them to draw upon elements of the ICP when they consider it necessary.

Despite the fact that all of the nurses in this study seemed to have a deep passion for ensuring that dying patients had a dignified death, there were also several incidents in which the nurses had failed to achieve this objective. Poor care became especially evident in stories with low staffing, high workload, and unskilled assistants. Moreover, the nurses in these stories were acting independent of the ICP. This fact alone would suggest that the poor care afforded to these patients might not have been related to the ICP in itself, but to external contextual factors.

...It was last summer, and I was in charge of 32 patients that night...I was walking “on the top” that shift, and there was this patient on the ICP...I remember it as chaotic...They (assistants) could not dispense medications, nor

did they know the patients or the routines...So I had to be everywhere!...Then there was this patient who had an epileptic seizure...And also this new patient from the hospital...So you see, it was very chaotic...I did not have the time I wanted for the dying patient, nor his relatives...When I entered the patient's room, I only did what was most necessary...Turn the pillow and moisten the mouth...I remember when I was checking off the boxes at the end of the shift, I had this guilty feeling that I had not been doing a sufficiently good job... (Lilly)

In summing up the incarnation of the mystery, a story began to unfold from the empirical material about a standardized instrument that at first glance seemed to be the genesis of proper and dignified end-of-life care. However, at second glance, it appears that the nurses were in fact working independently of the ICP in the provision of ongoing bedside care to the dying patient. How are we to understand this? Does this mean that the ICP is redundant? Why, then, were the nurses so positive about the use of the ICP? In the next section, we attempt to answer these questions, hoping that this will lead us to solving the mystery.

### **Towards a Solution of the Mystery**

In this section, we will present and discuss three possible solutions to the mystery: (I) the ICP is not compatible with the complex problems of dying patients; (II) the ICP is a myth with symbolic power; and (III) using the ICP as a loosely coupled system contributes novel effects to nursing practice. There may be several other clues and ways of understanding nursing practice in relation to the ICP, but this is our interpretation and contribution to solving the mystery.

#### ***I. The ICP is Not Compatible with the Complex Problems of Dying Patients***

Caring for dying patients in nursing homes can be highly complicated because these patients often suffer from multiple comorbidities (Hjort, 2010). Most of these patients have dementia (Selbaek, Engdal, Benth, & Bergh, 2014), which makes their situation more complex due to the difficulties in estimating death, as well as assessing symptoms within this population (Husebø & Husebø, 2004). In line with Rittel and Webber (1973), these problems are considered to be complex problems, which presupposes a certain amount of slack or flexibility (Schön, 1973) in the care of the dying patients. This means that the nurse must be fully present in the situation with the suffering patient, "seeing with her whole body" to understand the patient's condition (Martinsen, 2000). These problems are too complex to be solved by following an objective criteria (Rittel & Webber, 1973). Moreover, Martinsen (2000) argues that the nurse who follows such an objective criteria within any investment of their own professional body of knowledge and experience is in danger of losing their ability to discern the holistic needs of the patient. This is especially true of those needs that might fall outside the scope of the rational system.

In line with Max Weber (1978), we can describe the ICP and nursing practice in terms of their own logics: *instrumental rationality* and *value rationality*, respectively. The ICP belongs to what Weber (1978) labels instrumental rationality, where the ICP is built upon a rigid system of means to achieve their ends. The system is not customized within the context in which it is to be used. Nursing practice, on the other hand, belongs to a value rationality in which the nurses must act according to both internal factors as complex problems and external contextual factors, such as time, staffing, and management. This would suggest that the two logics are inherently incompatible, indicating that it is difficult to achieve a tight coupling

between the ICP and nursing practice. This is also consistent with systems theory, which claims that a tightly coupled system is only achieved when the units within the system share the same variables (Glassman, 1973).

From this perspective, we are now approaching one clue in the mystery puzzle: in order to give proper care to the dying, nurses must customize the care of the individual patient because of their complex problems and their unique situation in general. Acting independent of the ICP becomes a matter of necessity if the nurses are to give their dying patients proper care. In other words, the nurses solve the conflict between instrumental and value rationality by tinkering with the system; that is, the nurses adjust and decouple their practice from the ICP as it suits them. This tinkering process is a phenomenon that has been described previously in social science research (Engebretsen, Heggen, Wieringa, & Greenhalgh, 2016; Gabbay & le May, 2004; Lampland & Star, 2009; Timmermans & Epstein, 2010). However, this is perhaps the first time that this phenomenon has been described in relation to the ICP (Liverpool Care Pathway). As we will show in the last section of this article, this result is of considerable importance in terms of how we should evaluate the ICP in relation to care outcome and highlights the importance of in-depth studies used for the validation of standardized instruments.

## ***II. The ICP is a Myth with Symbolic Power***

If the nurses in this study were working independent of the ICP, how then are we to understand their positive attitudes in relation to the ICP? We believe a new clue in the puzzle is to be found in the *symbolic power* of the ICP. To understand this, we have to look more closely at the origins and functions of the standardization approach.

Having a formal education in nursing previously served as an outward symbol of trust to the general public (Grimen, 2008). This has, however, changed according to the development of a more individualized society. That is, with the individualization of our society, the autonomous human being has had their rights secured through strict legislation (Pasient- og brukerrettighetsloven, 1999). This has put further pressure on the institutions where services take place, and also on the individual health worker to deliver proper treatment and care (Helsepersonelloven, 1999). At the same time, both institutions and individual health workers have been put under pressure to deliver economically efficient services. In this regard, nurses have become street-level civil servants, carrying out the laws and public policies of the society (Lipsky, 1980). This means that nurses are legally mandated to deliver both qualitatively effective and economically efficient care at the same time. In sum, trust, by virtue of education, is no longer a priori given, but must be carefully considered through the justification of experience (Kant & Meiklejohn, 2009). With this perspective in mind, we can say that the individual nurse has acquired a new role in which they have developed responsibility for creating trust by showing that care of the patient is consistent with legal regulations.

In this regard, the standardization approach provides a redemptive solution to the numerous complex tasks that health care workers, including nurses, confront on a regular basis. Health authorities have, through the years, proclaimed the sacredness of the standardization approach as a means for ensuring the provision of high-quality treatment and care to patients. As such, we have come to believe in the approach. In other words, the standardization approach has entered the world with great symbolic power: so long as we follow the standardized criteria, the rights of the individual and the duties of the health care worker are being fulfilled, at least symbolically. Transferred to the ICP, this means that the ICP has the ability to generate ideas about proper care, and simultaneously represents a record of the fulfillment of proper care. When proclaiming the use of this instrument, it gives an outward impression of quality of care,

thus signaling *trustworthiness* to the public. In addition, accusations of poor care can be countered by referring back to the documentation of care.

However, it is only after we have collated all of this information that the clues begin to emerge. We wanted to understand *why* the nurses seemed so positive about the ICP despite them working independent of the instrument. One possible solution to this mystery might lie in the symbolic power of the ICP, where the ICP functions as a myth with great symbolic power, one that is being used as a means to legitimize the realities of nursing practice (Christensen, Læg Reid, Roness, & Røvik, 2007; Meyer & Rowan, 1977).

### **III. The ICP Creates a Novel Effect on Nursing Practice**

Although the symbolic power of the ICP might seem to be a reasonable solution to the mystery, it still seems that something is missing in the overall mystery puzzle. As we will show below, the ICP does not simply function as a soaring myth; the myth, in fact, becomes tangible when it is used loosely as a coupled system. This seems to be the final clue needed for understanding why the nurses were so positive about the ICP, despite them not actually using it as intended.

As already shown, the tinkering process is necessary to create proper and individually tailored care for the patient. Had the nurses been forced to rigidly use the ICP as detailed, the implementation would probably have come up against a wall of resistance because of the incompatible values that exist between the ICP and nursing practice. However, when the nurses were allowed to use the ICP in their own way, there exist what Latour (2005) calls *weak inscription*. Meyer and Rowan (1977) would describe that as a “loosely coupled system”. Common for both of these theories is that they have the potential to generate novel effects that go beyond the original scope of the creator of the ICP (Latour, 2005; Meyer & Rowan, 1977). This seems also to be the case in our study.

By allowing a loose coupling between the ICP and nursing practice, it seems that the ICP has the potential to create a *common culture* among health workers. As shown in the quotes above, the nurses spoke of a shift from curative to palliative care with the use of the ICP. They also described the formation of consensus statements or common agreements among the nurses and other health care professionals, that the patient was dying, and about what general elements of care were necessary when using this instrument. When analyzing the empirical material, it appears that this common culture is created and maintained through two different processes: First through the process of internalizing knowledge into the individual clinical mindlines at a micro level, and then through the process of creating collective clinical mindlines at a meso level. Before we elaborate upon this, however, we will explain the concept of clinical mindlines.

Clinical mindlines is a concept developed by John Gabbay and Andr e Le May (2004, 2011), meaning that health care workers are not using explicit knowledge (e.g., evidence-based guidelines, ICPs, protocols, etc.) in a rational-linear manner. Instead, they are negotiating evidence and internalizing knowledge to their existing *bank* of personalized, theoretical, and experiential knowledge. In other words, they are storing different kinds of knowledge in their heads, which they incorporate into a complex synthesis of individual practice-based evidence (Gabbay & le May, 2004). This *knowledge bank* is what is referred to as “clinical mindlines,” meaning that there is a complex web of tacit, internalized guidelines that health care workers use as shortcuts in concrete situations with the purpose of providing the individual patient with proper and customized care.

The empirical material in this study supports this concept of theory, both at the micro and meso levels. For example, the nurses in this study told stories about “having the points and the content of the ICP in their head” and where “the points in the ICP appear or pops up when



assessing the patient.” This suggests that the nurses were internalizing knowledge (which lies within the plan) into their existing clinical mindlines when using the ICP as a loosely coupled system.

In the mindlines concept, Gabbay and Le May (2004, 2011) claim that explicit knowledge goes through a process of *collective* sensemaking or negotiation between health care workers at the meso level before being internalized into the individual clinical mindlines. However, we found that individual nurses seemed to negotiate the benefits of using the ICP with themselves at the micro level before internalizing this knowledge into their existing mindlines. This might be related to the fact that the nurses had less time for collegial discussions as compared to general practitioners, which represented the bulk of the sample in the study by Gabbay and Le May. Although the question “What is in it for me?” has not been expressed explicitly in relation to the nurses, this would otherwise seem to be a reasonable question in this negotiation process, especially in consideration of the nurses’ role as street-level civil servants and their dependency on being the recipients of trust from the general public.

When the ICP has become internalized into the individual clinical mindlines, it seems that the ICP also functions as a *sharer of knowledge* at the meso level, where knowledge becomes institutionalized as organizational knowledge (Örtenblad, 2013). Or, by using the concept of clinical mindlines, we can say that the ICP has the potential to “create collective clinical mindlines.” This means that the ICP creates some kind of collective sensemaking among the health care workers. For example, the empirical material is telling a story about the ICP as a means of generating discussions among the health care workers as to whether the patient is dying or not. The empirical material also tells a story about speaking the same language and agreeing on the care of the patient. In other words, the ICP leads the health care worker to a state of collective sensemaking and understanding (Tsoukas & Vladimirou, 2001) in end-of-life care. These collective clinical mindlines, therefore, can be seen as the *mediator* in the process of creating a common culture among health care workers. This common culture is of great importance, not only for the health care workers, but also for the dying patient and their relatives. It ensures an overall approach to end-of-life care that is founded upon *practice-based evidence*, which is highly customizable to the needs of the individual patient.

In summation, this shows that the ICP, when loosely coupled, has the potential to create novel effects for nursing practice, both at micro and meso levels. This seems to be the last clue in the puzzle toward understanding why the nurses in this study were so positive in relation to the ICP despite actually working independent of the instrument. This leads us to the final section: how these results might have broader relevance outside the scope of this study.

### **Developing the Solution to the Mystery: Conclusion and Implications**

In this study, we have elucidated in-depth knowledge about the nature of nursing practice when using a standardized instrument in the care of dying patients. Our study revealed that nurses experienced the ICP as a useful tool in end-of-life care, although they were actually working independent of the ICP in the provision of ongoing bedside care to the dying patient. This discrepancy has not been identified in previously published studies of the ICP (Liverpool Care Pathway). In our study, we processed this discrepancy as a mystery, in which we found three possible solutions: (I) the ICP is not compatible with complex problems, (II) the ICP is a myth with symbolic power, and (III) the ICP creates a novel effect on nursing practice.

That the ICP is not compatible with complex problems seems to provide one viable solution to the question of *why* the nurses were working independent of the ICP in the provision of ongoing care. In other words, the problems of dying patients were simply too complex to be solved by rigidly following an objective criteria. The nurses subsequently found it necessary

to tinker with the ICP in order to ensure that dying patients received proper and dignified care. This tinkering process is not an unknown phenomenon in the general research field of social sciences (Engebretsen et al., 2016; Gabbay & le May, 2004; Lampland & Star, 2009; Timmermans & Epstein, 2010). However, this is perhaps the first time that this phenomenon has been described in relation to the ICP (Liverpool Care Pathway).

The paradox in our study can be recognized as the Emperor's New Clothes, a story in which everyone believes in the standardization approach because of its symbolic power, but in which the approach actually functions as a wandering myth. In other words, the nurses in our study want to maintain the use of the ICP because of its ability to legitimize their practice and to engender trust among the public. As such, the idea that the ICP is a myth with symbolic power provides a reasonable clue to solve this mystery.

This is not to say that all standardized procedures or guidelines work as wandering myths. As such, it is important to distinguish between *tame* and *complex* problems. Rittel and Webber (1973) describe tame problems as those that are easy to define, and where there exists a clear solution to the problem (e.g., the procedure of cardiopulmonary resuscitation). In such cases, a standardized approach might be expedient. In opposition to this, complex problems are far harder to define, and represent situations for which there might not be a standard or default solution to the problem (Rittel & Webber, 1973). As such, standardization is difficult to implement in a rational or linear manner.

To delve deeper into the emperor metaphor, we also found that the emperor did not wear the clothes that he *claimed* to have worn. Interestingly, however, he is not totally without clothes. What appears when looking more closely is that he is wearing a strange piece of clothing that is not common for an emperor. Or, to use another metaphor, the myth has been given tangible flesh when there is a loose coupling between the standardization approach and nursing practice. This means that the ICP has the power to create novel effects (i.e., different clothes) on nursing practice, which goes beyond the original scope of the approach. In this study, we have shown how the ICP has the ability to create a common culture among health care workers through a process of individual and collective sensemaking, which we labeled clinical mindlines. This common culture is of great importance, not only for the health care workers, but for the dying patients and their relatives who will become the recipients of end-of-life care based upon the best available, practice-based evidence (Figure 1). The idea that the ICP creates a novel effects on nursing practice, therefore, seems to be our last clue as to why the nurses were fond of the ICP, despite the fact that they were working independent of the ICP in the provision of ongoing bedside care.

Based on the evidence in our study, our analysis demonstrates that the accusations of poor care related to the ICP (Husebø et al., 2017; Høeg, 2015; Johansen & Nave, 2016; Neuberger et al., 2013; Nilsen, 2015), may be false. This means that the nurses are not using the ICP instrumentally or as a tick-box exercise, as accused. On the contrary, it turns out that nurses using the ICP work in much in the same way as they did before the introduction of the ICP. The difference is, however, that the content of the ICP has been integrated into the totality of their nursing knowledge, such that they use elements of the ICP when they consider it necessary. This would suggest that the poor care might be related to external contextual factors, which exist independent of the ICP. This suggestion, however, must be validated through additional ICP studies.

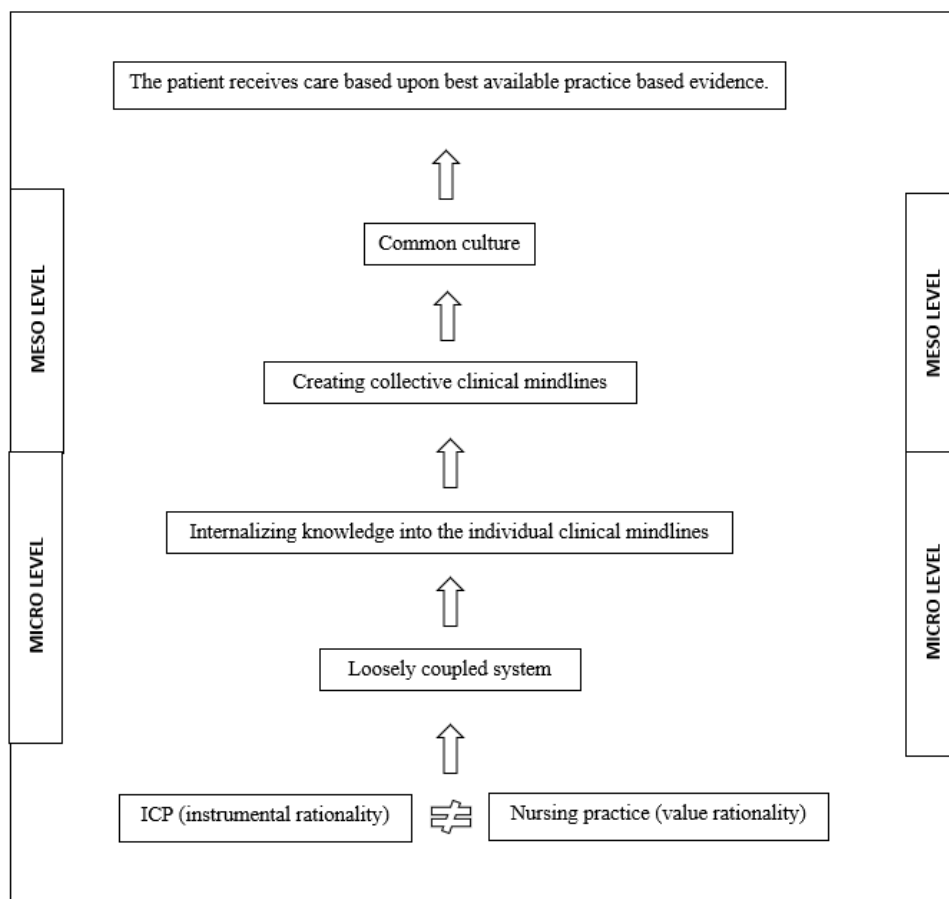


Figure 1: *ICP – creating novel effects of nursing practice.*

In this last section of our paper, we have summarized and conceptualized (given a theoretical contribution) the main results of the study. As such, our findings are analytically generalizable to theoretical propositions and not to populations (Yin, 2014). That is, our findings are posed at a conceptual level higher than that of our specific sample, thereby having relevance outside the scope of this study. One limitation of the study, however, is that this research study only involved the investigation of *one* integrated care pathway, the Liverpool Care Pathway. Additional studies (of other ICPs) are needed to enhance the domain (standardization within health-care services) successively, consequently also ensuring the external validity of the findings.

Despite this limitation, we though believe our findings give an essential *understanding* (cf. footnote 3) of the domain of standardization, which is of great value for both politicians, health authorities, managers, and health care workers concerning organization and practice within the health-care services. In summation, we believe that our findings function as a reminder that we should not assume that standardized instruments are necessarily being used in a rational linear manner. Nor is it desirable to use the instruments in this way. When it comes to complex problems, our study shows that allowing a loose coupling between the standardized instrument and nursing practice is an important key in preventing so-called tick-box exercise or instrumental care. In fact, our study shows that tinkering with standardized instruments is necessary to promote qualitatively efficient care, based upon the best available practice-based evidence (here: individual and collective mindlines).

Finally, our study also demonstrates how abductive reasoning can reveal valuable in-depth knowledge about a research phenomenon. We have transcended the empirically-given and produced knowledge at a deeper level, which is concealed to both robust study designs and

to soft study designs that intend to investigate empirical material at a surface level. In fact, our study reveals the importance of a qualitative, abductive approach in the early stages of the validation process of a standardized instrument. This provides an opportunity to capture important contextual knowledge that might be of considerable significance, both for society in general, and as a stepping stone toward further research (e.g., studies with so-called *robust* designs). Paradoxically, robust studies lacking in this element of knowledge risk producing knowledge with low internal and external validity, since these studies might not measure what they claim to measure.<sup>6</sup> In summation, this highlights the necessity of a paradigm shift within our society, where so-called *soft evidence* is to be acknowledged as valuable and valid knowledge in the development of the existing knowledge base.

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<sup>6</sup> If, for example, it transpires that all of the nurses are working independently of the ICP and researchers are unaware of it, then they are in fact measuring the individual nursing practice (clinical mindlines) instead of the use of the instrument.

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