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Prognostic awareness in advanced cancer patients

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Abstract

Being aware of the severity of medical condition is a key precondition for patients to be involved in advance care planning. This assumption is in literature referred as prognostic awareness, and good communication with physicians is one of the factors that significantly influence it. This dissertation thesis is focused on this topic of prognostic awareness in patients with advanced cancer. The aim is to describe this phenomenon and identify other factors that are related to the prognostic awareness in patients with advanced cancer. The author of this dissertation thesis participated in a three-year project, which was supported by the Grant Agency of the Czech Republic (IMPAC study), which aims to map the preferences of patients with advanced disease and further describe factors related to prognostic awareness and assess its stability over time. The secondary goal was also to describe how patients with a serious diagnosis and their loved ones evaluate participation in a research study.

In the introductory chapter of this dissertation thesis, we describe the concept of prognostic awareness, methods of measuring it and the goals of this work. The dissertation thesis includes 4 publications that are focused on this topic and 1 publication that responds to the secondary goal of this dissertation thesis. The publications are followed by a discussion in which we deal with all our findings in the context of the latest evidence available on this topic.

This work proves that prognostic awareness is a complex phenomenon and lists the factors that can influence it. In addition, we have also shown that the level of prognostic awareness does not change over time and therefore, it is probably a stable phenomenon. Our work also showed that patients and their loved ones do not mind participating in the research study, even almost half of them considered it as an interesting experience. Our results prove that when delivering bad news, it is necessary to know the preferences and wishes of the patient and apply an individual approach.

Key words: prognostic awareness, communication, delivering bad news, quality of life, cancer

Abstrakt

Být si vědom závažnosti svého zdravotního stavu je klíčový předpoklad pro to, aby pacienti mohli být zapojeni do plánování své budoucí péči. Tento předpoklad se v literatuře označuje pojmem prognostické uvědomování a dobrá komunikace s lékaři je jedním z faktorů, který jej významně ovlivňuje. Tato disertační práce se zabývá tímto tématem prognostického uvědomování u pacientů s pokročilým onkologickým onemocněním. Jejím cílem je popsat tento fenomén a identifikovat další faktory, které ovlivňují porozumění vlastní prognóze u pacientů s pokročilým onkologickým onemocněním. Autorka této disertační práce se podílela na tříletém projektu, který byl podpořen Grantovou agenturou ČR (IMPAC study), jejímž cílem zmapovat preference pacientů s vážným onkologickým onemocněním a dále popsat faktory, které souvisí s prognostickým uvědomováním a prozkoumat jeho stabilitu v čase. Vedlejším cílem bylo také zmapovat, jaké je pro pacienty s vážnou diagnózou a jejich blízké účastnit se výzkumné studie.

V úvodní kapitole této disertační práce popisujeme koncept prognostického uvědomování, způsoby jeho měření a cíle této práce. Součástí disertační práce jsou 4 publikace, které se tímto tématem zabývají a 1 publikace, která reaguje na vedlejší cíl této disertační práce. Publikace jsou následovány diskusí, v níž se zabýváme všemi našimi zjištěnými poznatky v kontextu nejnovějších evidence, která je na toto téma dostupná.

Tato práce prokazuje, že prognostické uvědomování je komplexní fenomén a přináší výčet faktorů, které ho mohou ovlivňovat. Vedle toho jsme také ukázali, že míra prognostického uvědomování se s časem nemění a jedná se pravděpodobně o stabilní fenomén. Naše práce také rovněž ukázala, že pacientům ani jejich blízkým nevádí účast ve výzkumné studii, dokonce téměř polovina z nich to považovala za zajímavou zkušenost. Naše výsledky dokazují, že při sdělování závažných zpráv je nutné znát preference a přání pacienta a uplatňovat individuální přístup.

Klíčová slova: prognostické uvědomování, komunikace, sdělování závažných zpráv, kvalita života, onkologické onemocnění

1. Introduction

New therapeutic possibilities in cancer care which are available enable patients with advanced cancer to live longer than ever before but it also brings more possibilities in care and requires more involvement of patients in the decision-making process. This requires health care providers to respect the autonomy of patients, respect their values and choices and individualized approach. Making choices and decisions is an important way of expressing patients' autonomy that enables them to take an active part in their medical decision-making process which is a good way how to support their dignity (Houska & Loučka, 2019).

In situations when the primary goal is not to cure the disease anymore, balancing the patients' values and their future treatment options is not possible without adequate communication and a shared view on the disease trajectory. Moreover, a systematic review by Belanger et al. showed that patients want this active role and prefer to be active in the decision-making process (Bélanger et al., 2011).

Therefore, the patients' and relatives' involvement in those decisions is desirable as a key feature of patient-centred care (Frank, 2009). To ensure that patients can make medical decisions, which truly reflect their preferences and wishes, improving patients' understanding of their healthcare status is a fundamental task for all healthcare providers. Facilitating understanding of the prognostic of patients lies at the centre of these efforts. The overall goal of this thesis is to focus on how patients with advanced cancer understand their disease and which factors influence this process of the development of prognostic awareness.

1.1 Prognostic awareness

The ability to understand the disease, its seriousness and potential future trajectory is behind the concept of *prognostic awareness* which is central to this thesis. In 2014 a systematic review on this topic was published and it included all studies till 2012 (Applebaum et al., 2014). The main aim of this review was to look at how prognostic awareness is measured in different studies. It was found that there is a lot of variation in the conceptualization of prognostic awareness, and it may be seen also as a unidimensional construct, as well multidimensional construct (Applebaum et al., 2014). This review was recently updated, and a concept analysis was done to provide the evidence-based definition of prognostic awareness (Kühne et al., 2021). This recent systematic review brought conceptualization of this concept using content analysis and define it as:

PA (prognostic awareness) primarily comprises the appropriate estimation of chances for recovery (i.e., incurable disease), knowledge of limited time to live and the appropriate estimation of shortened life expectancy, and secondarily, the appropriate estimation of therapy goals as well as knowledge of the course of a disease, (page 3, Kühne et al. 2021). This operational definition highlights different ways how we can look at this phenomenon and how we can measure it. We can ask patients whether they think that their disease could be still cured, or what is their life expectancy or what is the goal of their therapy. A recent large meta-analysis showed that a very low number of advanced cancer patients understand their prognosis well, the mean prevalence of accurate prognostic awareness was 49.1% (95% CI: 42.7%–55.5%, range: 5.4%–85.7%) (Chen et al., 2017). This number indicates that there are still a lot of patients who do not understand fully the seriousness of their condition but the mechanism of how the prognostic awareness is developed and if it changes throughout the disease remains unclear.

2. The aims of this thesis

This thesis has 3 aims:

- 1) To describe factors that may be associated with prognostic awareness in cancer patients

The plausibility of this aim will be tested with a systematic review of studies exploring the associations between accurate prognostic awareness and various factors.

- 2) To assess the stability of prognostic awareness in patients with advanced cancer throughout their disease

Regarding this aim, we postulate the following hypothesis:

H0: There is no significant change in prognostic awareness in patients with advanced cancer throughout their disease.

This aim will be tested with a longitudinal assessment of prognostic awareness in advanced cancer patients.

- 3) To describe the experience of patients and their caregivers with palliative care research

The third aim will be assessed with this hypothesis:

H0: Patients with advanced cancer do not mind participating in the palliative care research.

Besides prognostic awareness, this thesis has a secondary goal which is methodological, and it is focused on the experience of patients with advanced cancer with participation in research. This goal will be achieved in two steps. For the first participants in a cross-sectional study about patient preferences, we will ask patients to evaluate their experience with this study and we will also ask them about their motivation to participate in the research. The second is to ask participants in a longitudinal cohort study to evaluate their experience.

This thesis is based on a monothematic compilation of 5 peer-reviewed articles in which we aimed to answer our hypothesis.

3. Methods

This thesis is a part of the project Integrative Model of Prognostic Awareness in Patients with Advanced Cancer (IMPAC study) (Loucka et al., 2017). This work was supported by Czech Science Foundation (grant number 17-26722Y). The principal investigator of this study was my supervisor Dr Martin Loučka. This project aimed to explore factors that patients with advanced illnesses consider as important and develop an integrative model of prognostic awareness that would provide insight into the mechanism of the decision-making process in advance.

The IMPAC project had 3 stages. In Stage 1 we conducted semi-structured interviews with patients with advanced cancer and their relatives and focus groups with health care providers. The goal of this stage was to explore what factors they consider important at the end of life. In Stage 2 we developed a questionnaire based on the results from Stage 1 and in this questionnaire patients with chronic disease, their relatives and physicians were asked to rank the importance of presented factors. During Stage 1 and 2 we also conducted a systematic review on factors that are associated with prognostic awareness to prepare a structured interview for Stage 3.

In Stage 3 we recruited a cohort of patients with advanced cancer and their relatives and over 9 months we collected data from them at least 3 times. For inclusion criteria, we have used a 12-month surprise question used by treating oncologists meaning that the physicians answered adversely to the question: “Would it surprise me if this patient dies in the next 12 months?” (Hamano et al., 2015). Using a structured interview, we asked them about their prognostic awareness (using 3 different methods), information needs, and quality of life (using 2 different methods). Follow up measurements with patients as well as their caregivers were conducted either in person or by phone. Their treating physicians were asked the same

questions about prognostic awareness, and they also provided other clinical data about patients. In Stages 2 and 3 patients and their relatives were asked at the end of the questionnaire and structured interview how they evaluate participating in the research.

4. Results

4.1 First aim

Our first aim was completed by a systematic review in which we identified 102 factors that were found to have a significant association with prognostic awareness. Using thematic analysis, we grouped them into 7 groups. Demographic factors, factors related to coping, health condition factors, psychological factors, factors associated with end-of-life care, factors related to communication and factors related to relatives. Some of the factors have negative associations with prognostic awareness, some of them have positive and for some of them we found mixed results. The most studied factors were depression, anxiety and quality of life and they were associated with accurate prognostic awareness and with inaccurate prognostic awareness. This article uncovered the vast complexity of prognostic awareness, and the results suggest that this phenomenon is very difficult to interpret. Most of the reviewed studies also used the cross-sectional design that highlights the need for longitudinal assessments to validate our knowledge about the development of prognostic awareness. This article serves as the foundational knowledge base for this thesis, and it helped us in designing the data collection methods for the latter parts of the IMPAC study.

Our next step related to the first aim was to assess the relations between prognostic awareness and quality of life (which was identified as a very important factor related to prognostic awareness) also in the Czech population of patients. Part of this thesis was also the adaptation and standardization of the tool for measuring the quality of life. We have decided to adopt a specific tool for measuring the quality of life in the general population of palliative care patients that would have wider use in future research. The Integrated Palliative Outcome Scale (IPOS) was developed at King's College London and has been translated and used widely across the world as one of the most reliable tools to measure the quality of life in palliative care patients (Sandham et al., 2019). Standardization of IPOS allowed us to measure the quality of life in the IMPAC study with a robust tool. IPOS was found to be reliable (Cronbach alpha 0.789), and the adaptation process was successful.

Data from IPOS were collected in the longitudinal study and we analysed data from the baseline measurement in the IMPAC study with a sample of 129 patients. We tested the association between the composite measure of prognostic awareness (using 3 different

methods for assessing prognostic awareness) and quality of life using IPOS and a single-item quality of life scale. We found a negative association between accurate prognostic awareness and quality of life ($p= 0.02$). However, detailed analysis that was allowed by using our validated IPOS tool showed the association was significant only for the physical domain of quality of life ($p= 0.002$), not for the emotional and communication domain. These results suggest that the association between prognostic awareness and quality of life might be explained by the fact that patients aware of their diagnosis are usually in the advanced stage of their disease with a worse symptom burden. Therefore, prognostic awareness itself does not have to be related to emotional distress in patients which is often feared by clinicians.

4.2 Second aim

In our second aim, we assessed the longitudinal stability of prognostic awareness. We used 3 different measures for assessing prognostic awareness and we compiled the scores of all three questions with a potential outcome of 0 for no correct answers in any of the three questions (patient not aware), one point for at least one accurate answer (patient partially aware), and two points for all questions answered accurately (patients considered to be aware of their prognosis). We found that 16 % of patients were aware, and 58 % were partially aware. We did not find any significant association between prognostic awareness and other factors such as gender, education, health information needs etc. Caregivers were slightly more aware of the prognosis of their loved ones than patients which was not associated with patients' prognostic awareness (agreement rate 59%, weighted kappa 0.348, CI = 0.185–0.510). Longitudinal analysis showed that prognostic awareness seems to be a stable concept over time, therefore it might be influenced by other aspects such as personality traits.

4.3 Third aim

Our last aim was focused on methodological aspects of palliative care research. We wanted to know how patients evaluate their participation in this type of research. This aim was achieved in two steps. The first study was a cross-sectional questionnaire study assessing patients' preferences and priorities regarding end-of-life care. Participants were asked to evaluate their experience on a five-point Likert scale and use an open-ended question about their motivation to participate. The second evaluated experience was their participation in the longitudinal cohort study on prognostic awareness. This study revealed that patients and their caregivers do not mind participating in research (53 % in the first sample and 48 % in the second sample) and about 30 % of the participants even rated their experience as interesting.

The results did not differ in the cross-sectional study or longitudinal study. The motivation of participants was to support research, improve care or express their opinion. The trusting relationship also plays important role in that. There was not any difference in the evaluation between patients and caregivers. These results imply that clinicians and staff do not have to be afraid to offer their patients and their caregivers the opportunity to engage in research, of course, while respecting and following the formal ethical procedures.

5. Discussion

5.2 First aim

This thesis aimed to describe prognostic awareness in more detail and bring some new theoretical knowledge about this phenomenon. The main aim was to look at possible factors that influence prognostic awareness and to assess its longitudinal stability throughout the disease. The second goal of this thesis was to assess how patients and their caregivers evaluate participation in palliative care research.

Our systematic review revealed that accurate prognostic awareness was associated with some factors positively, with some factors negatively and with mixed results in many others which makes the interpretation of the role of these factors very difficult. Our results showed that prognostic awareness is associated with demographic factors, coping strategies, mental health, different amount of communication with the physician and different levels of end-of-life care.

Some of the reported factors were assessed in more studies with mixed results, therefore it will be needed to conduct a meta-analysis to have a reliable conclusion about the correlates of prognostic awareness. This discrepancy might be also explained by the fact that the development of prognostic awareness might be influenced by specific personality traits. However, so far only some specific aspects of personality were assessed and it was found that dispositional optimism was related to less accurate prognostic awareness (Soylu et al., 2016). Personality traits such as lower neuroticism, conscientiousness and openness were found to be associated with better health behaviour (Rochefort et al., 2019), health-related quality of life in advanced disease (Ibrahim et al., 2015), and linked to specific medical decision-making preferences (Butler et al., 2016; Flynn & Smith, 2007). However, to our knowledge, there is no study specifically exploring the relationship between the core personality traits and prognostic awareness.

Our cross-sectional study showed that worse quality of life was associated with accurate prognostic awareness, however detailed analysis showed that these findings were valid only for the physical domain, not for emotional or information subscales of the IPOS. There were some similar findings to ours (Costantini et al., 2015; H. Lee et al., 2020). Most available cross-sectional studies speak contradictory though indicating a negative relationship between accurate prognostic awareness and emotional quality of life (El-Jawahri et al., 2014; Fan et al., 2011; Greer et al., 2014; Kim et al., 2013; Yanwei et al., 2017) or indicating no significant association between emotional quality of life and accurate prognostic awareness (H. Lee et al., 2020). The discrepancies in results might be explained by different trajectories of developing prognostic awareness. This suggests that delivering bad news about prognosis by a physician might be a protective factor against emotional distress in patients. This is supported by the fact that patients who get the information from their physicians have a better quality of life, and less emotional distress compared to those who learnt it by chance or from their worsening condition (Yun et al. 2010).

Overall, these inconsistent results suggest that the association between quality of life and prognostic awareness is much more complicated and probably other confounding factors influence the relationship such as coping strategies, personality traits and or prognostic acceptance (Tang et al., 2020). On the other hand, quality of life itself in patients with advanced cancer is influenced by various factors, such as worse performance status (Kuon et al., 2021), gender (Laghousi et al., 2019; Oreel et al., 2020) age, education (M. K. Lee et al., 2013) or type of cancer (Kim et al., 2013).

5.2 Second aim

Our longitudinal cohort study showed that prognostic awareness remains stable throughout the disease. There is a piece of scarce evidence about the stability of prognostic awareness, however similar studies also confirmed the stability of prognostic awareness throughout disease (Hsiu Chen et al., 2017; Kang et al., 2020). However, some of the studies reported short survival as a factor related to the accuracy of prognostic awareness which implies that prognostic awareness might change toward death (Greer et al., 2014; Hsiu Chen et al., 2017; Kim et al., 2013; Liu et al., 2014). This suggests that toward death more patients may develop prognostic awareness, however, this was based on cross-sectional analysis, and it was not supported by our longitudinal data.

The difference in our results might be also explained by the problems related to the conceptualization of prognostic awareness. In our study, we used 3 different methods to

assess prognostic awareness that has been widely used in previous research and surprisingly we got very different results analysing them separately. When we asked about their health condition (question 1), 34 % of patients in our sample reported accurate prognostic awareness, 22 % when we asked about the probability of being cured (question 2) and 67 % when we asked about the goal of their treatment (question 3). Our results suggest that these methods do not measure the same phenomenon, or they measure various aspects of prognostic awareness. Some of them may measure only the awareness of status (e.g. healthy, seriously ill or terminally ill) but some of them might measure also the acknowledgement of patients (e.g. what is the goal of treatment or life expectancy etc.) (Hui et al., 2021) which might be two different things for some of the patients. This is illustrated by another study which found that 33 % of patients with metastatic cancer stated that the primary treatment goal was to cure their cancer, although 45 % of these patients also reported that their oncologist's goal was not to cure (Nipp et al., 2017). This inconsistency might be explained by the conceptual framework of preparedness for death which was developed by Tang and her colleagues (2020). Their model presents prognostic awareness as a cognitive component of preparedness for death and does not imply that patients with accurate prognostic awareness are already prepared for the end of life care decision making (Tang et al., 2020) and therefore, they might answer questions used in research such as ours differently. This highlights the need for validation of the method for assessing prognostic awareness which will help us in understanding this phenomenon by asking patients the right questions.

The important question that is remaining is what are the turning points which help patients to develop prognostic awareness? Factors that help patients to prepare themselves for understanding prognostic awareness are well described in a qualitative study by (Walczak et al., 2013). Walczak et al. found that there are some factors which are important in developing patients' readiness for discussion about prognosis. From the patients' perspective, it is the experience with severe symptoms, to have mental capacity and the disease has to be accepted by family carers (Walczak et al., 2013). Relationship with the physician was also important as well as their perceived communication skills (Walczak et al., 2013). As prognostic awareness seems to be a very complex phenomenon it was suggested to use a prognostic continuum when thinking about this with patients (Hui et al., 2021). Hui and his colleagues use this continuum which includes patients' readiness to engage in prognostic conversation and developing prognostic awareness followed by supporting prognostic acceptance before involving patients in the decision making process (Hui et al., 2021). This continuum is very

useful for clinical practice because it also suggests what kind of intervention should be provided to patients to comfort them.

5.3 Third aim

We found that most of our participants did not mind taking part in these studies, and half of them even considered it an interesting experience. This result was similar for patients as well as for family carers. Our findings are consistent with other studies on this topic (Moorcraft et al., 2016; Terry et al., 2006; Todd et al., 2009; White & Luce, 2004) which indicates that we do not have to be afraid of inviting patients with advanced disease or their families in research because they are capable of assessing their ability and willingness to participate. Their motivation for participation is consistent through various studies and it is mostly driven by the desire to help (in improving care or supporting research) or the desire to express themselves (opportunity to talk) (Bloomer et al., 2018).

But what was the reason for this study? Conducting palliative care research is seen as a very challenging procedure for several reasons (Beaver et al., 1999; Davies et al., 2010; Harris & Dyson, 2001). One of the main reasons is the phenomenon of gatekeeping (Ehrlich & Walker, 2018; Gonella et al., 2021; Pleschberger et al., 2011). Gatekeeping is a situation when health care staff, family caregivers or other involved parties prevent eligible patients from participating in a study mainly because they want to protect them from additional burdens (Kars et al., 2015). As prevention of gatekeeping, it might help to further engage staff in the project (Zermansky et al., 2007). This could be done by showing them all relevant materials to the project, asking them about their opinion (Seymour et al., 2005) and also using materials that will provide enough information for potential participants as it might be the only thing that they will see before they decide (Pleschberger et al., 2011).

This was also the situation of our IMPAC project where it was very crucial to explain well the purpose of the study to physicians in the hospital and get at least one of them at each site on board for cooperation and help with the recruitment. It was partly supported by money reimbursement, however, we do not think that the amount of money was big enough that it would serve as the only motivation for their participation in research (Largent et al., 2012).

Taking together it is essential to provide data that patients in palliative care are not too burdened by the research and they can decide for themselves. We hope that our data may serve in future as evidence for justifying research in this field for stakeholders, ethical committees, or health care staff in the Czech Republic or elsewhere.

6. Conclusion

This thesis showed that prognostic awareness is a very complex phenomenon which is related to various factors with inconsistent data about the direction of their association. We also showed that prognostic awareness is a stable phenomenon which does not change throughout the disease. We also found that patients and their relatives do not mind participating in research even when they are facing serious and advanced stages of their diseases.

Future directions in this area should explore the association of prognostic awareness with core personality traits which may help to understand inconsistent results related to some correlates of prognostic awareness. Such research may also help in developing interventions focused on the development of prognostic awareness. Another problem in this area is the fact that most of the methods that are used for assessing prognostic awareness do not have their psychometric properties evaluated therefore their reliability and validity are limited. This needs to be done and the involvement of patients in the process of developing the assessment tools would be highly beneficial.

After extensive studying of this topic, it seems that it is part of some more complex process. We have to distinguish between prognostic awareness, which is a cognitive process, and prognostic acceptance, which is an emotional process. The next step is to evaluate the effectiveness of communication interventions that are being developed (Bloom et al., 2022) and to assess how and whether they can influence both these processes. It might be also important to understand better whether this conceptual framework also works for family caregivers. Also, it will be important to assess prognostic awareness in other chronic diseases than cancer, where the trajectory is more complicated and to explore the possible differences in the development of prognostic awareness across patient populations.

This thesis has several important implications for clinical practice. Our results showed that there is a need for honest and effective communication about prognosis as most of the patients in our sample did not have an accurate understanding of their condition. It might be helpful to use specific techniques or protocols (such as SICP – Serious Illness Care Program)(Bernacki et al., 2015) to be successful in delivering this information to patients that have not been previously validated in the Czech Republic. In clinical practice, it might be important to use the concept of the prognostic continuum and adjust communication to the

readiness of patients and other related factors. To conclude, it is important to use an individualized approach to patients and also assess their values and preferences as soon as possible, preferably before starting the actual prognostic disclosure.

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8. List of publications (IF, 2021)

1. publications *in extenso*, on which dissertation is based

a) with impact factor

Vlckova, K., Polakova, K., Tuckova, A., Houska, A., & Loucka, M. (2022). Association between prognostic awareness and quality of life in patients with advanced cancer. *Quality of Life Research*, 1-8.

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IF= 3.89

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IF= 3.29

Vlckova, K., Tuckova, A., Polakova, K., & Loucka M. (2020). Factors associated with prognostic awareness: A systematic review. *Psycho-Oncology*

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Vlckova, K., Hoschlova, E., Chroustova, E., & Loucka, M. (2020). Psychometric properties of integrated palliative outcome scale: Czech standardization and validation. *BMC Palliative Care*, 19(1), 1-8.

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b) without impact factor

Vlčková, K., & Loučka, M. (2018). *Dotazník pro měření kvality života v paliativní péči IPOS – Manuál pro použití české verze*. Praha: Centrum paliativní péče

2. publications *in extenso* without relations to the topic of dissertation

a) with impact factor

Janoušková, M., Vlčková, K., Hrcuba, V., Klučková, T., Motlová, J., & Bankovská Motlová, L. (2022). The Challenges of Inter-Role Conflicts for Peer Support Workers. *Psychiatric Services*, appi-ps.

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