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EMPIRICAL STUDIES

Relative's suggestions for improvements in support from health professionals before and after a patient's death in general palliative care at home: A qualitative register study

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Abstract

Introduction: The efforts of relatives in providing palliative care (PC) at home are important. Relatives take great responsibility, face many challenges and are at increased risk of poor physical and mental health. Support for these relatives is important, but they often do not receive the support they need. When PC is provided at home, the support for relatives before and after a patient's death must be improved. This study aimed to describe relatives' suggestions to improve the support from health professionals (HPs) before and after a patient's death in general PC at home.

Methods: This study had a qualitative descriptive design based on the data from open-ended questions in a survey collected from the Swedish Register of Palliative Care. The respondents were adult relatives involved in general PC at home across Sweden. The textual data were analysed using thematic analysis.

Results: The analysis identified four themes: (1) seeking increased access to HPs, (2) needing enhanced information, (3) desiring improved communication and (4) requesting individual support.

Conclusions: It is important to understand and address how the support to relatives may be improved to reduce the unmet needs of relatives. The findings of this study offer some concrete suggestions for improvement on ways to support relatives. Further research should focus on tailored support interventions so that HPs can provide optimal support for relatives before and after a patient's death when PC is provided at home.

KEYWORDS

home care, palliative care, relatives, support improvements, support needs

INTRODUCTION

The efforts of relatives (family and others, such as friends) are important in providing palliative care (PC) at home [1–3]. In this context, relatives take great responsibility, face many challenges and are at an increased risk of poor physical and mental health [2, 4–6]. Therefore, adequate support for relatives is important; despite this, relatives

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involved in PC have unmet support needs [7–10]. Support for relatives aims to prevent ill health and promote the ability to cope with difficulties before and after a patient's death [11]. Supporting relatives often involves health professionals (HPs), such as doctors, nurses and nursing assistant offering relatives assistance in this care, giving informative, emotional and practical support. Emotional support is usually provided in some form of conversation, while practical support may involve, for example, relief in the home or help with household chores. Education, information, personalised relief, individual or group support sessions and various forms of guidance and counselling are particularly important [12]. Relatives should also be informed of the possibility of using the available cash benefit – financial compensation for a relative who gives up paid work to care for or be with a dying loved one – for the care of closely related persons [12, 13]. Although support for relatives is a fundamental component of PC, relatives do not receive the support they need before or after a patient's death [10, 14–17]. Support for relatives requires improvement [18] and since PC involves a holistic approach to care, the physical, psychological, social and existential needs of both the patient and the relatives should be met, including support for relatives before and after a patient's death [11, 19].

PC includes general and specialised forms and, in home care in Sweden, general PC is provided to a greater extent than specialised PC. General PC is usually provided by HPs with basic knowledge in PC, without it being their main activity [13]. Previous research describes challenges for relatives caring for a person receiving PC at home [3, 6, 8]. Wang et al. [20] highlighted that relatives in different healthcare settings demonstrate different levels of unmet needs, but the highest level is reported in the home setting. Support for relatives is not optimal, neither before nor after a patient's death [15, 16, 21], and there are deficiencies in the support provided to relatives when PC is provided at home [14, 22]. Further research on relative's unmet support needs in the home PC setting is needed [3], and in general PC at home in Sweden, support for relatives before and after a patient's death needs to be improved [23]. Therefore, this study aimed to describe relative's suggestions to improve the support from HPs before and after a patient's death in general PC at home.

METHOD

Study design and respondents

The study had a qualitative descriptive design based on data from open-ended questions in a survey collected from the Swedish Register of Palliative Care (SRPC). The Standards for Reporting Qualitative Research checklist was followed to improve the transparency and study quality [24]. Adult relatives involved in general PC at home across Sweden constituted the study population. The respondents were relatives of deceased persons aged 47–106 years – 34 (41%) of the deceased persons were male and 49 (59%) females. The respondents were relatives of persons who had died of cancer (75%), cardiovascular disease (7.5%), lung disease (1%), stroke (1%), dementia (1%), other neurological disease (1%), multimorbidity (7.5%) or other diseases (6%). See Table 1 for respondents' characteristics.

TABLE 1 Overview of the respondents' characteristics.

	Total ***n*** **= 83**
Type of relative	
Spouse or partner	39
Child (adult)	38
Other relative or friend	6
Geographic	
Northern Sweden	20
Middle Sweden	1
Southern Sweden	62

Data collection and the survey

The open-ended questions used in this study are part of a survey designed for relatives from the SRPC, a national quality register in Sweden. Established in 2005, the SRPC aims to improve end-of-life care for patients and their relatives for all deaths regardless of diagnosis, gender, age or place of death. The SRPC's survey for relatives can help assess how general or specialised PC has been provided in different healthcare settings in Sweden; HPs invite relatives to answer the survey within 3 months after a patient's death. Aside from support for relatives, the surveys also cover topics regarding information to the patient, the patient's care needs, symptoms and symptom relief and the disease that caused the death.

A total of 160 relatives involved in general PC at home across Sweden answered the survey in the SRPC between March 2016 and March 2022. Of these 160 survey respondents, 83 answered one or more of the open-ended questions. The answers to four open-ended questions (without limitation of words) from the survey were requested from the SRPC and included in this study. Three of the questions were answered using a five-point scale, where relatives were asked whether they had received the support they needed/were satisfied with the support they received before and after a patient's death. They could also be

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answered with free-text responses. Only the free-text responses from these three questions were included in this study. The fourth question, one regarding suggestions for improvement, could be answered only with free-text responses. Only the suggestions for improving support were extracted from the free-text responses from these four questions; these constituted the analysis. See Table 2 for an overview of the questions used in the survey.

Data analysis

The analysis was based on 129 responses from 83 relatives, ranging from one to eight sentences long. Some of the sentences shared detailed experiences; others were brief. The number of questions answered per relative varied from one to three. The initial reading of the responses demonstrated that the majority contained experiences regarding support improvements. The textual data from the four open-ended questions were analysed using an inductive thematic analysis described by Braun and Clarke [25]. Initially, all the free-text responses were read repeatedly to gain an overview and familiarise the researchers with the data. Then, the data were organised to generate the initial codes. The codes describing similar content were grouped together, reviewed and re-coded if necessary. The codes were collated into potential themes, at a semantic level, related to support. The themes were reviewed by all the authors by reading through the codes and the entire data set, forming a thematic map, and the essence of each theme was defined.

Ethical considerations

This study was conducted according to the Declaration of Helsinki's research ethics principles and ethical guidelines [26]. An application for ethical clearance was obtained from the Ethical Review Authority in Sweden (diary number: 2022-01668-01) before conducting the study. Data from the SRPC were provided de-identified, and there was no information about the respondents other than their relationship to the deceased patient.

TABLE 2 Description of the questions used in the survey.

Questions from the survey for relatives
Do you have any suggestions for improving support for you as a relative?
Are you satisfied with the support that you as a relative received from healthcare before the patient's death?
Are you satisfied with the support that you as a relative received from healthcare after the patient's death?
Did you receive the support you needed from the healthcare system before the death of your loved one at the ward/care team where your loved one died?

RESULTS

The findings were organised into four themes: (1) seeking increased access to HPs, (2) needing enhanced information, (3) desiring improved communication and (4) requesting individual support. An overview of the themes is presented in Figure 1.

Seeking increased access to HPs

The relatives described seeking increased access to HPs to improve support when PC is provided at home. They desired access to 24-hour support from HPs, expressing disappointment that support was unavailable around the clock. The relatives requested increased access to support at night, when help was less accessible than in the day. The relatives also expressed stress regarding their inability to reach the nurse at night when needed; sometimes, the nurse's number did not work at all. The relatives suggested that one improvement regarding support could be to provide them with a 'back-up' number to increase the possibility of contact during the night. In addition, they suggested that access to a PC team on weekends could be beneficial, as it was currently only available on weekdays.

> At night, the telephone of the night nurse did not work. It was stressful not being able to reach them when needed. It would be good to have a backup number to call.
>
> (Respondent 4)

The relatives also described that the possibility of gaining access to HPs to monitor patients during the final period of life should be improved. The relatives described that the HPs had denied them support to monitor the patient the final few nights, though they had expressed a wish for it in order to sleep, themselves. The relatives also requested short-term relief from HPs for a few days to recover.

> I would have liked to get health professionals watching over the patient on the last night, but it wasn't possible because it was a weekend, I was told.
>
> (Respondent 88)

The relatives further described a need for improved support through access to HPs, gaining assistance with faster administration of pain relief. They expressed that it could

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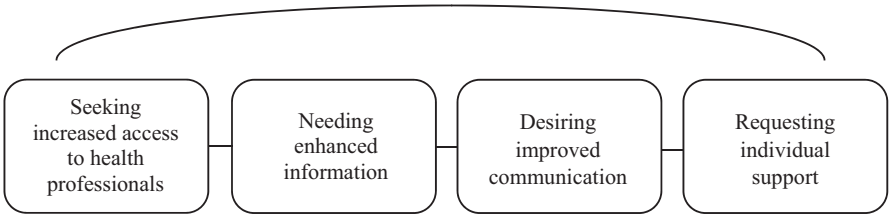

FIGURE 1 Improvements in support for relatives before and after a patient's death in general PC at home.

take several hours before they received such help after contacting the HPs, causing them distress and anxiety. The relatives also expressed a desire for greater continuity – for the same HPs to visit them in their homes as much as possible, especially at the end of the patient's life.

> Faster insertion of pain relief upon contact with nurses in home care. The patient had severe pain. Relatives contacted home care to get quick help with pain relief. The contact was made at 19:22. Pain relief was not given until around 01:00. When contacted by telephone at about 20:30 to speed up the insertion of pain relief, an unpleasant treatment was experienced.
>
> (Respondent 37)

The relatives also sought increased access to HPs after the patient's death. They described that support from the HPs after the patient's death had been absent altogether and expressed a desire for the HPs to offer counselling for that period of time. They described a feeling that once the patient had died, no more support was considered necessary by the healthcare system.

> No support, no contact at all.
>
> (Respondent 110)

The relatives also expressed that they would have preferred a visit from the nursing assistants, nurses and doctors after the patient's death, as opposed to only one of them. Since the relatives had spent much time with them, they wanted closure with all the team members who had been part of PC at home.

> I wish the health professionals in home care who most often visited us could come and say goodbye to me.
>
> (Respondent 87)

Needing enhanced information

The relatives expressed a need for enhanced information to improve support for them, describing that they did not receive sufficient or any information at all. This included, for example, information regarding the patient's illness, condition and whether the patient was at the end of life. They also requested to receive information about the possibility of using the available cash benefit for the care of closely related persons and regarding what they could get help with at home. For example, the relatives had not been informed about the possibility of getting help picking up the patient's medicine, so they had to go to the pharmacy themselves. This caused unnecessary stress and disappointment as the relatives felt they were missing valuable time with the patient.

> What I was disappointed about was that I had to leave my mother to pick up medicine at the pharmacy. The last day she was contactable! I had to visit 2 pharmacies before I got everything. Then the nurse said that they had everything to bring. That was not OK. I missed time unnecessarily. Unnecessary stress.
>
> (Respondent 110)

The relatives also described that the information provided by the nurses to the nursing assistants needed to be improved, for example, regarding the patient's condition and symptoms. Some care tasks were not being appropriately performed by nursing assistants, requiring the relatives to perform care tasks, such as oral care, during the patient's final period at home.

> Information about the patient's condition to nursing assistants at home. The performance of certain care tasks has not always been performed properly during the period of illness.
>
> (Respondent 116)

In addition, the relatives described that they wanted the information shared between the HPs, such as nurses and nursing assistants, day and night staff and relatives, to be improved. They expressed that misunderstanding between the day and night staff resulted in information not being conveyed to them, leading to, among other things, missed medication for the patient. Also, the relatives suggested

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that the information regarding symptom relief needed to be improved so that both the relatives and HPs know what doses apply and how often they should be given. They also requested information about when they could provide medicine in another form to the patient when the pain relief in the pain pump was insufficient. One suggestion for improvement was to receive written information regarding symptom relief, for example, when using a pain pump.

> Written information about, for example, morphine pump, since we did not know in what time interval we could press the pump or that we could have been able to give in tablet form when the morphine pump did not help.
>
> (Respondent 21)

The relatives also described that the information they received beforehand was insufficient, for example, when transferring the patient from the hospital to the home. They described the need for enhanced information to become better prepared in the home before the patient was sent home from the hospital.

Furthermore, the relatives described the need for enhanced information in caring for the patient after death. They would have liked to received information about the possibility of preparing the patient at home, washing the patient, combing the hair and putting on selected clothes, etc.

Desiring improved communication

The relatives expressed a desire for improved communication with the HPs to support them, as communication with the HPs was not working optimally. They requested more conversations about the patient's condition and described that improvements in support could be made in raising and discussing difficult topics regarding death, as they found it difficult to communicate about it and accept that the patient would die. They also wanted help in contacting a counsellor or psychologist to talk to when needed.

> I found it very difficult to take in/accept that my husband was dying...Perhaps I should have received more help in address this difficult topic.
>
> (Respondent 145)

In addition, the relatives suggested improved communication with and between different HPs to coordinate care so that they would not have to contact different healthcare institutions. They described not knowing who was responsible for what and having to request meetings themselves, which was time-consuming and unnecessarily stressful for them. The relatives also wanted more one-on-one conversations and communication with doctors, as they felt that doctors' support was non-existent for the relatives and other HPs.

> Coordinate care so that relatives do not have to call home care, health centre and hospital. It is not easy for me as a relative to know who is responsible for what.
>
> (Respondent 144)

Furthermore, the relatives desired improved communication with the HPs to support them after the patient's death. They described that this support had been minimal, such as only a quick phone call or no communication at all with the HPs. The communication with the HPs after the patient's death was inadequate, and the relatives desired more conversations with the HPs to discuss how they were feeling, among other things. Relatives requested more conversations, as one conversation was perceived as too little.

> Minimal, one phone call, would like to have more.
>
> (Respondent 70)

Requesting individual support

Several of the relatives requested improvements in the individual support. They related that the HPs must become better at listening to both the patient and the relatives, and that the HPs were quick to draw conclusions about the need for care without listening to the patient or relatives. They described that HPs must become better at taking care of the whole person and not solely carrying out selective actions or just trying to remedy a specific situation that has arisen. Furthermore, they wanted the HPs to become better at seeing the individual, as they felt that the HPs generalised and compared them to others. In addition, the relatives expressed that the HPs did not know enough about PC and how to conceive of 'wholeness'. One suggestion to improve the individual support for them was to get help from a special team of HPs trained in PC. This applied to both nurses and nursing assistants.

> Some health professionals were quick to draw conclusions about a care need without clearly listening ... Generalised, and compared us with others. They did not realise that there are unique cases.
>
> (Respondent 144)

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The relatives also expressed that the HPs needed to become better at identifying the need for aids. They described that they wanted aids for the patient earlier, such as a hospital bed, a pressure-relieving mattress and seat cushion, but that the HPs denied it.

Furthermore, the relatives requested individual support after the patient's death. They related that support improvements needed to be made in the follow-up in order to express how they were doing. For example, they described that the HPs had only come to their homes to collect the aids and leftover medicine after the patient's death. Furthermore, the relatives requested more support in dealing with grief after the patient's death. Relatives would have appreciated a personal meeting some period of time after the death, not just a phone call. They highlighted the importance of support after the patient's death and described that they needed to, among other things, reflect on the entire course of the disease, finding it difficult to remember what had happened and when.

> After mom died, they only came to pick up aids and leftover medicine. No follow-up on how relatives are doing ... It would be desirable for the nurse to call dad to hear how he is doing. And see if any further intervention is needed for him, etc.
>
> (Respondent 96)

DISCUSSION

The unmet support needs experienced by relatives when PC is provided at home are well documented. This study aimed to describe relative's suggestions for improvements in support from the HPs before and after a patient's death in general PC at home. The findings show that the relatives requested improvements in information and communication. These results confirm those of previous studies showing that some of the most common unmet needs for relatives in different healthcare settings are information needs, including illness, treatment and care-related information and effective communication with HPs [20, 27–29]. This suggests that HPs still fail to meet the support needs of relatives in PC in terms of, for example, adequate information and communication. The results of this study show that the relatives desired improvements in support through information regarding, for example, the patient's illness, condition and end-of-life transition. They also desired more communication about the patient's condition and about raising and discussing difficult topics about death. Previous studies have highlighted the importance of informing and communicating with relatives about the patient's near end [6, 30, 31]. However, previous studies [30, 32] have shown that HPs can experience difficulties discussing death and dying with relatives. Barriers that may make it difficult for the HPs to provide adequate support to relatives, such as sufficient information and communication, may include the HPs underestimating of the relative's information needs [33], lack of time to communicate, feeling unprepared or uncertainty regarding the disease trajectory and prognosis [34, 35]. Other barriers may be related to the fact that the patient and/or relatives do not accept or understand the prognosis [34, 35]. Even if there is uncertainty in the patient's prognosis and expected disease trajectory, previous studies have shown that relatives think it is important for HPs to continue to communicate openly and clearly with them about this. The relatives request information on the prognosis and disease trajectory despite the uncertainty and risk of creating expectations and choices based on an unreliable estimate [27, 29, 33]. Therefore, improvements in the support for relatives should include sufficient and clear information and communication by HPs based on the individual needs of the relatives. Since the findings of this study suggest that the relatives in general PC at home still lack optimal support in terms of information and communication, a tool to aid HPs in succeeding in improving information and communication support based on the needs of relatives may be the Carer Support Needs Assessment Tool (CSNAT). According to Ewing and Grande [36], CSNAT can be used to identify the areas where relatives require improved support; its use in clinical practice has shown a reduction in the caregiver burden for relatives [37, 38].

Furthermore, relatives suggested improvements in the support to them after a patient's death, as the support provided to them had been minimal or absent altogether. They suggested improvements through increased access to the HPs and more counselling and conversations with the HPs after the patient's death. Relatives further described that support improvements should be made in the follow-up to understand how they were coping and see their need for necessary support interventions. They also wanted more support in dealing with grief after the patient's death. Previous research has shown that support to relatives after a patient's death is not optimal [16, 21]. A previous study regarding the support for relatives in general PC at home showed that 81.2% were satisfied with the support they receive after a patient's death but that one-fifth were not [21]. O'Sullivan et al. [16] found that 21% of relatives in different care settings have no follow-up conversation after a patient's death, even though

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they would have liked it. Support after a patient's death is important to help relatives cope with the grief due to the losses that occur during the time of illness and after death. Support after a patient's death can reduce the risk of psychiatric and psychosomatic disorders that grief can otherwise lead to [11]. Also, follow-up conversations are helpful for the bereavement process, and previous studies have shown that relatives express a need for bereavement follow-up conversations with HPs after a patient's death [16, 39–41]. Milberg et al. [39] found that the follow-up procedure helps relatives experience a feeling of being recognised individuals with their own needs. Therefore, it is important that HPs, as part of the efforts to improve support for relatives, make it a routine to offer support to all the relatives in need of it after a patient's death, including follow-up conversations. O'Sullivan et al. [16] suggested that one way to support HPs in their end-of-life communication with relatives could be to clarify the procedures related to follow-up conversations in national guidelines for PC, including information on, for example, what topics can be discussed. Since this study's results showed that the relatives wanted more than just one conversation after a patient's death, this could also be clarified in guidelines for PC. Further research is needed on how HPs can support relatives at home after a patient's death to guide improvements in this important aspect of PC.

In this study, several of the relatives emphasised that support for them would improve if the HPs could better listen to them. They described that HPs must become better at looking at 'wholeness' and 'seeing the individual', since they felt that HPs generalised and compared them to others. Seeing wholeness is part of the definition of PC [19] and is also consistent with a person-centred perspective, starting from the person's holistic needs [42]. Since the relatives involved in PC at home have unmet support needs, a person-centred perspective might contribute to understanding how to meet these needs and improve the support to them. In PC, the relative's need for support often changes over time depending on the course of the patient's illness and the situation of the relatives [23, 43]. Diffin et al. [44] highlighted that HPs must support relatives systematically and holistically. Support for relatives must be timely, individualised, and tailored to the needs of the relatives at all stages of the caring trajectory [44, 45]. Diffin et al. [46] stated that the support for relatives in PC should be person-centred. Anker-Hansen et al. [47] stated that by adapting a person-centred perspective, the relatives are likely to have their needs met to a greater extent than what is accomplished today. However, Ekman et al. [48] state that there is a variety of significant challenges to putting person-centred care into clinical practice, though HPs acknowledge it to be an important part of care. Oosterveld-Vlug et al. [27] and Ongko et al. [33] found that relatives find it important that HPs are person-focused in PC at home. Also, all the identified themes in this study regarding improvements to support can be related to the component ´person-centred processes´ of the framework described by McCormack and McCance [42]. Working from a person-centred perspective could enable HPs to improve support based on the individual needs of relatives at home before and after a patient's death.

Strengths and limitations

It is a strength of this study that its data were collected from a national quality register with relative-respondents across Sweden. Despite this, the study has limitations that should be noted. First, there are different views on the use of open-ended questions in surveys in qualitative research. Even if the data from the open-ended questions may impose constraints on the responses and lack conceptual richness due to few sentences [49, 50], the depth and detail of feelings revealed in the open-ended responses can help to explain and answer qualitative research questions and provide meaningful insights into people's experiences [50]. Also, there is no information on which relatives were invited to respond to the survey or whether those who declined differed from those who participated. Though there is no information (such as gender or age) about the relatives who responded to the open-ended questions (other than type of relative) O'Cathain and Thomas [49] mean that respondents' comments are still valuable data, even when the respondents may not represent the entire sample. Regardless, this study offers concrete suggestions from relatives for the improvement of support in general PC at home.

Furthermore, there is no information regarding other experiences that might influence the answers to the open-ended questions in this study, such as when during the disease trajectory they would have liked the support, previous care contacts or different family dynamics. The results regarding the support for relatives after a patient's death may have been influenced by when the relatives were invited to respond to the survey, as some may not yet have been offered this support. Also, as the relatives answer the survey after the patient's death, it is worth considering that they are in a difficult situation that could influence how they assess the support they received. Despite these limitations, this study provides important knowledge regarding improvements in support for relatives when general PC is provided at home.

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CONCLUSIONS

It is important to understand and address how the support to relatives may be improved to minimise the unmet support needs of relatives. Sufficient support for relatives is essential as they are important partners when PC is provided at home. There is a need for HPs to more effectively identify what support is requested to improve the support for relatives and target the available support actions. The findings of this study offer some concrete suggestions for the improvement of the support of relatives when providing general PC at home. Addressing these improvements can enable HPs to reduce the unmet support needs of relatives. These findings can also guide the development of guidelines on support for relatives or guide the development and implementation of tailored support interventions in future studies. This, in turn, can contribute to the improvement of support and enable HPs to provide optimal support to relatives. This study shows the value of concrete suggestions for improvement of support to relatives and the significance of ongoing research and development to provide optimal support for relatives both before and after a patient's death when PC is provided at home.

AUTHOR CONTRIBUTIONS

Elina Mikaelsson Midlöv, Terese Lindberg and Lisa Skär jointly conducted the design and methodology of this study. Elina Mikaelsson Midlöv processed the data. All authors participated in the analysis work. Elina Mikaelsson Midlöv drafted the article. Terese Lindberg and Lisa Skär have critically revised the text regarding intellectually important content. All authors have given final approval for publication and take public responsibility for all its parts.

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CONFLICT OF INTEREST STATEMENT

The authors declare that there is no conflict of interest.

DATA AVAILABILITY STATEMENT

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

ETHICS STATEMENT

An application for ethical clearance was obtained from the Ethical Review Authority in Sweden (diary number: 2022-01668-01) before conducting the study. Data from the Swedish Register of Palliative Care were provided de-identified, and there was no information about the respondents other than their relationship to the deceased patient.

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