

## Being a hospice volunteer

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The aim of this study was to obtain an understanding of what it means to be a hospice volunteer in a country without a tradition of hospice or palliative volunteer care services.

Ten volunteers from three different hospices in Sweden were interviewed. Their narratives were interpreted with a phenomenological hermeneutic method. Three themes were disclosed: motives for becoming involved in hospices, encountering the hospice and encountering the patient. The interpretations disclose a need for the volunteer to be affirmed as a caring person and received in fellowship at the hospice. Positive encounters with a hospice are closely related to personal growth. Volunteers feel rejected if their need for meaning and for belonging to the hospice is not satisfied. This shows that hospices need to set goals in terms of volunteer support, particularly regarding existential issues following the encounter with the hospice and the patient. *Palliative Medicine* 2005; **19**: 602–609

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### Introduction and aim

Previous research on volunteering in palliative care has, to a large extent, been concerned with issues of organization, such as economics, recruiting, education, the role of the volunteer and their support.<sup>1–7</sup> Volunteer experience has also been explored, including the type of stress associated with this kind of volunteering,<sup>8</sup> and the motives behind volunteering.<sup>7</sup> Jeppsson and Grassman,<sup>9</sup> assert that there are many reasons for working as a volunteer. Both pure altruism and individualistic self-interest are listed. The most important reasons, however, are the welfare of the other person, the task in itself or the mutual exchange. Roessler *et al.*,<sup>10</sup> probed into the motives, among other things, of the volunteers who are active within hospices. Emerging motives included helping others, giving of their free time to work they believed in, personal experience of the death of close relatives, self-fulfilment and personal growth, and learning more about life and death. These motives are verified in other studies,<sup>2,7,11,12</sup> as well as, for example, by Claxton-Oldfield *et al.*,<sup>13</sup> who describe such motives as leisure, personal gain, altruism and civic responsibility. Franzén's study,<sup>12</sup> into volunteer experience in Swedish hospice care describes volunteer activities and role issues. Although activities at a hospice include, explicitly or implicitly, encounters with death and dying, we have not found any

study into existential meanings of being a volunteer within hospice or palliative care.

Volunteers are considered a unique resource in the palliative care team, completing and enhancing the value of the professionals.<sup>3,14,15</sup> In different places throughout the world, the most common tasks for the volunteers are housekeeping, assisting in personal care, shopping and help with transportation. They are also given indirect tasks, such as fundraising and office work. Further, volunteers support the family in their process of mourning both before and after the death of a patient.<sup>7,15</sup> This is the situation in many western countries which have a strong volunteer program tradition. Nevertheless, although the philosophy and care approach of palliative care is well established in Sweden, organized volunteer services in this sector are not widespread.

Elements that are important for the work of the volunteers in hospice organizations include recruiting and education, contacts with patients, relations with employees and other volunteers, and the level of involvement the volunteers themselves experience in the hospice organizations.<sup>2</sup> For a volunteer to identify with and be integrated in the hospice organization, they must acquaint themselves with its purpose and goals and with the people working at the hospice. They will also need time to adjust to the organization, and will need ongoing support to be able to maintain their identification with the hospice.<sup>11,15</sup> As a member of the team, the volunteer must be given such information about the family or the patient as is necessary for them to be able to fulfil their tasks.<sup>3,8</sup> The volunteers also need to share their thoughts and feelings with personnel and with other volunteers in order to feel part of the team.<sup>11</sup>

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The personal benefits of working in the non-profit sector, as reported by Field and Johnson,<sup>2</sup> are that you feel you are doing something important and you come out of yourself to experience a lot of things from other perspectives. In exchange for the time that the volunteers give to hospices, they receive appreciation, gratitude and friendship. This also constitutes a reason for continuing as a volunteer. Reasons for discontinued involvement with a hospice may be that the volunteer feels taken for granted by staff, experiences a change in personal relationships and is disappointed with the lack of relevant information and support from hospice personnel.

The aim of this study is to obtain an understanding of what it means to be a hospice volunteer in a country without a tradition of hospice or palliative care volunteer services.

## Method

A qualitative design was chosen for the study. Since the focus was on meanings in personal experiences including existential dimensions, we chose a phenomenological hermeneutic approach,<sup>16,17</sup> out of the interpretation theory of Ricoeur.<sup>18,19</sup> This approach facilitated exploration of how the phenomenon of being a hospice volunteer in a certain context is lived, and in what ways it might be interwoven with different aspects from the life-world, such as life history, actual situation, and anticipated future. Interpretation of meanings thereof aims to enhance future understanding of volunteer experience.

### Context of the study

In Sweden, where this study was performed, palliative care generally belongs to the public sector in home care settings,<sup>20</sup> complemented by palliative consulting teams and a few independent hospices.<sup>21</sup> Sweden has a century-long tradition of voluntary work, though not within palliative care. The mindset of voluntary work has been shaped by the traditions of the non-profit sector, including for instance, independent churches and cultural groups, or various organizations working for specific interest groups, such as pensioners, or for the promotion of sports. Voluntary work also features strongly in the social sector, providing support and help of various kinds, for instance, programs targeted at helping drug addicts or homeless people.<sup>9,22,23</sup>

The hundred or so volunteers that were involved with 15 Swedish hospices in 1999 are viewed as a complement to professional palliative care.<sup>24</sup> The objective of including volunteers in services is usually stated as 'to enrich life and bring a sense of "nonmedicalization" to hospice care'. Activities provided by volunteers are usually diverse. What presently differs between hospices is the structure of volunteer co-ordination and support; from

an occasional introductory followed by ad hoc support, to comprehensive, continuous support programs. The participation of volunteers within hospices in Sweden has caused discussions with the unions, because of the supposed risk of volunteers replacing employees.<sup>4</sup>

### Participants

Three hospices in central and western parts of Sweden with three to ten years of volunteer experience were strategically sampled for the study, and were chosen because of their different styles of organization (public health care as well as non-profit foundations) and extent and orientation of volunteer services. The nursing managers at each of these hospice units were contacted for permission to interview volunteers, who they contacted utilizing convenient sampling. The managers started out by verbally describing what participation in the study entailed, after which the volunteers in each hospice were provided with written information and asked to participate. The ten volunteers, nine women and one man, who were asked to participate, accepted. All had Swedish as their first language and were aged between 30 and 70. Three were retired, one had retired prematurely because of illness, and the remaining six were active in their professions. These professionals worked within hospitals, churches and schools, with students and in the service sector. The interviewees had been active as volunteers for between six months and ten years.

### Ethics

The study was approved by the Ethics Committee at the Medical Faculty, Gothenburg University, Sweden (Ö 081-02) and informed consent preceded participation. The anonymity of the volunteers was guaranteed as otherwise the volunteers may not have felt entirely open because of their loyalty to the hospice. Volunteers were also told that they could stop participating at any time.

### Interviews

The first author (BA), experienced within hospice care, conducted the narrative interviews. The participating volunteers were asked to suggest a place for the interview, and all took place in their respective hospices. Eight volunteers gave their consent to tape-record the interviews. Two did not want to be recorded, but accepted that written field notes would be taken during the interview. The opening question of the interview was: what made you become a volunteer here? Then the volunteers were asked to describe personal experiences from their voluntary work. The interviewer assumed the stance of a reflective listener,<sup>25</sup> interrupting only when clarification was needed for comprehension. In this way, the participants related personal stories from their volunteer experience. The interviews lasted between 30 and

60 minutes. At the end of the interview, the volunteers were given an opportunity to reflect over what had been said in order to unload thoughts and feelings the interview may have raised.

### **Process of interpretation**

The interviews were transcribed verbatim. The process of interpretation followed a phenomenological hermeneutical method with three interrelated steps; naïve reading, analysis of meanings of parts of the narratives, and interpreted whole.<sup>16,17</sup>

Firstly, the transcribed texts were approached with an open mind in order to acquire a sense of the text as a whole. We found that each participant told their story of being a hospice volunteer by describing everything they had been through, and how it had affected them.

We recognized that these stories included (1) the motives of the volunteers, their experiences of encountering (2) the hospice and (3) the patient. For this reason, we then analysed the meanings of the narratives with regard to these three aspects. During this second analysis, themes and sub-themes were distinguished and formulated by comparing similarities and differences of meanings in the narratives. Finally, for the interpreted whole, the meanings and understanding disclosed so far were critically brought together with our pre-understanding and ideas from the literature.

## **Results**

Three themes concerning the meaning of being a volunteer at a hospice were disclosed in the narratives. The first theme describes why volunteers get involved in hospices. In the second theme, the encounter with the hospice, the meaningful task and the longing for fellowship are emphasized. The third theme, the encounter with the hospice patient, concerns the desire of the volunteers to understand the needs of the patients, what they imagine occupies the patient's thoughts and time, and how to manage contact with the dying person. Excerpts from the volunteers' narratives are included in order to concretize and enhance understanding. These were translated verbatim into English when possible, however where necessary, we searched for similar English expressions in order to make sense of the translations.

### **Why volunteers get involved in hospices**

Volunteers described different motives for their involvement in hospices. Initially, some had a vague desire to be useful and to make others happy. For others, their own or a relative's sickness and distress was the reason for getting involved as a volunteer. These volunteers described a longing for social fellowship as a means of facilitating

support for themselves. Some had seen a family member die in hospice care and had stayed in touch with the hospice by becoming a volunteer. The social contact with the hospice, the security of being familiar with staff, and the opportunity of contributing something to compensate for the support that their own relative had been given, were important reasons. Volunteers had also received information about hospices through advertising in local papers or verbally from friends and other acquaintances from church, the Red Cross or hospice personnel.

### **Encountering the hospice**

The volunteers described their encounter with the hospice as 'getting to know the atmosphere of the hospice', 'being assigned a constructive task' and 'longing for fellowship'.

*Getting to know the atmosphere of the hospice.* All the volunteers perceived the hospice to be of a very special nature, wholly dedicated to helping and supporting people during the latter part of their lives. They experienced the atmosphere as peaceful, harmonious, bright, and warm the first time they visited. The volunteers mention that it feels like a home where visitors come and go and children run around playing, but, at the same time, has all the necessary facilities. The kitchen was described as the heart of activities: *'life is really brewing here'*.

The volunteers had questions about how the sick can be so positive and content: *'some of them have a power of life that is quite tremendous'*. They also noticed that the condition of the patients improved somewhat for a while after arriving at the hospice. One volunteer described it in this way: *'I never think of this as a place where you die but as a place where what is well rises to the surface'*. Another commented that there is always time for a massage or for someone to: *'fix him or herself up a little and get freshened up'*. The availability of different activities makes the volunteer experience the hospice as: *'a small society within society'*.

*Being assigned a constructive task.* Volunteers contributed by performing a variety of tasks that were additional to or an enhancement of the work performed by the regular staff, including the inter-professional healthcare team. How positive the experience of being a volunteer was largely depended on how the staff and the volunteer mutually succeeded in identifying suitable tasks and if the volunteer was given clear guidelines on how to perform the tasks. Simply coming to a ward without having a defined task can be experienced as a burden. One volunteer related how uncertain she felt about whether staff noticed that she was there or not. *'Many times I came here and asked if there was something I could do.'*

*I said I could bake something or... What do you want? And I guess they hadn't thought'. Volunteers may feel uncertainty about what is expected of them and they are afraid to 'cross over into the domain of the nurses'.*

The participants from one hospice emphasized that the place of the volunteers is not in actual nursing care. Instead, it is in helping the staff in various ways, so that they have more time for the patients. The volunteers from another hospice recounted how staff clearly told them that it was not that important for the volunteers to know what sickness the patients were afflicted with because the volunteer could still do a good job. One of the volunteers in this hospice said: *'That's right. You don't have to know that. But all the time those questions are there in the sick person and within me. I wonder what is wrong with him or her. It may be someone you see a lot, others you never see. I haven't felt OK to ask either, since somehow we have got to know that we don't need to know what's up with people. I have been careful not to ask. It's as if it's none of my business'.* This volunteer sees the patients when they come to the kitchen for meals. She is interested in the people she meets and feels disappointed not to be given any information at all about them.

It is essential that volunteers carry out their tasks to the best of their ability. The nursing staff told one volunteer who used to bake: *'It isn't that important for the cakes to be tasty, but they should smell good'.* For that individual, the result of the baking is secondary to creating a home-like environment. For the volunteer, however, the result of her effort is also of significance. Other volunteers described how they felt joy and satisfaction after performing their duties well and receiving positive responses from patients, relatives and personnel.

Some of the volunteers had expected to have more contact with the patients. One said she had expected to be given *'more opportunities to meet them in some kind of human relationship'.* Another volunteer who longed to do different tasks to those she was doing expressed her vision like this: *'It's not a matter of going on very long walks; it might just be that they need to get out to smoke, and it's boring to sit there alone. That's what I would like to do! Now I have got this thing. Now I attend to the flowers'.* This example shows that some volunteers are disappointed that staff do not care more about the personal preferences of the volunteers. However, volunteers expressed acceptance of the tasks they were given. One said: *'If I'm not content with this as far as I'm concerned, then perhaps I can do it for the sake of someone else. And it isn't that important for me to get personal satisfaction. I can do this because it's an act of charity or whatever.'*

*Longing for fellowship.* The volunteers' stories tell of a longing for fellowship – being part of a community. When they felt that their identification with the hospice was weakening, feelings of loneliness and not belonging arose. The volunteers viewed their voluntary assignments as stimulating, giving joy and contributing to their own personal development. Personal satisfaction was described this way: *'I feel happy inside, I have done something, and it gives me so much.'* The social contact – being there as a fellow and having something meaningful to do, as well as being met with openness, are significant components in the volunteers' descriptions. In this way, the volunteer will feel safe and participatory, creating a sense of *'being allowed to'.*

Where hospices provided structured volunteer support, an essential part in promoting a favourable reception from staff was the information session and follow-up that took place. Good information gives a sense of being on the team. However, even when a volunteer was positive about the information they had received, there may have been a lingering desire for deeper contact, such as getting an opportunity *'to sit down a little more and talk things through'.* Another volunteer expressed it this way: *'As a volunteer I can easily feel left out since I do not understand much of what's going on in the work'.* Other volunteers compared what they were doing in the hospice with functions at their regular jobs. Having a job that provided great opportunities for organizing their own work was likened to being *'in the hub everything revolves around'* – in contrast to volunteering. However, this participant reflected over this circumstance and said that in order for her to be content, it just was not that important to be in the centre: *'I expect to be on the periphery, but I want to know what ingredients there are in what we are cooking here.'* To her, those ingredients constituted information about and education in hospice work. She said that for her as a volunteer, it was necessary to keep learning about the important work that is being carried out, as volunteers are motivated by a wish to help. She also felt a need to share thoughts about life and death. She described feeling not important, *'because nobody takes any notice what I think about the situation'.*

The longing for fellowship as illustrated in the volunteers' stories may also be related to problems that some volunteers had with their own failing sense of wellness, for example due to sickness. When talking about their contributions at the hospice, one of these volunteers said that performing volunteer tasks had become *'support for my self-confidence. The task of being here to help is strengthening. Just being able to do the small things I do.'* In this way, performing volunteer tasks can open up the way for participating in a fellowship, a sense of belonging.

### Encountering the patient

Three different aspects were found in the volunteers' experiences of encountering the patient in the hospice: wanting to understand the needs of the patient, imagining what fills the patient's thoughts and time, and retaining the encounter with the dying patient.

*Wanting to understand the needs of the patient.* When encountering the patients, the volunteers described trying to adjust to them: '*...trying to see what that person needs and what I can give*'. Even conversation was adjusted to suit the patients: '*it's up to them to set the level for the discussion*'. Most of the conversations were about everyday things: '*to make things a little positive, it won't be that sad then*'. As previously indicated, the volunteers stated that they did not know very much about the condition of the patients, therefore they considered it extremely important for professionals to consider their responsibility to inform them, for instance when the volunteer went for a walk with a patient. Without this safeguard, the work becomes difficult and unsafe. One volunteer reported that she was told to ask the patients herself if someone wanted to go out, and felt very hesitant about it. '*I sure felt that a little, but I don't know these people. It would have been better if those who know them had said something, so that was a little hard since I didn't know for certain. Of course I picked those who looked relatively OK, but...*'

*Imagining the situation for the patient.* According to the volunteers, dialogues with patients did not touch on sickness, suffering and death as much as they did on common daily events. Among the volunteers, however, there were questions about how the sick themselves viewed their illness and pending death. The volunteers tried to understand when the patients were distressed or suffering, and whether or not they wanted to talk about it. Nevertheless, they saw it as an encouragement that many, in some way or other, were at ease with their fate and that their relatives usually seemed to manage.

Existential deliberations were expressed, such as: '*And I must say I think a lot about death when I come here and about this stage of life. How do the people here think? And how would you think if you were here?*' These are existential questions that everybody has whether they work in a hospice or not. '*I haven't really managed to get in touch with how they think or rather they haven't shared with me how they feel about dying*'. The volunteers understand that patients think about this, but hope and believe that they have worked it through with someone else. The participants found it of interest and value for volunteers to know a little about how staff view these questions, as a way of support, and this was put in the following way: '*They could at least give some*

*kind of information about it that would make me grow a little as a person, too.*'

*Retaining the encounter with the dying.* The volunteers who had no education in health-care emphasized that it had been useful to come to the hospice and get to know severely ill people: '*since this is a side of life I've known nothing about*'. This had imparted the feeling that: '*I'll manage it, yes, I will*'. According to the participants, death had come closer, so life was appreciated in another way. Some encounters touched them deeper than others because the volunteers identified more with some of the patients.

One of the volunteers pointed out that having a real opportunity to share thoughts and experiences of life and death with the staff is essential. She thought it was very important to say and understand that people who come to work at a hospice experience a lot of different things, regardless of what they do. '*And I experience a lot of things too, seeing the people come here and then no more. Suddenly, why isn't that person who was here last week, here any more?*' What this volunteer is expressing is the sense that she had not been given any opportunity to talk to someone about her experiences. The encounter with the dying person lingers on, reaching beyond the actual encounter, all the while everyday routines continue in the hospice. The fact is that the series of contacts the volunteer has had with a patient cannot always be rounded off, because the patient may have died when the volunteer next comes to the hospice.

None of the volunteers said that they brought heavy feelings home with them. What was experienced in the hospice was dealt with as the volunteers talked with one another and with the nursing staff: '*Most of it I unload while I'm here, so when I close the door, I'm done. But this is my personal attitude*'.

### Interpreted whole

What it means to be a volunteer in a hospice without traditions of volunteer services will be taken a step further here. Entering a hospice as a volunteer involves suffering and sorrow, but also joy in getting to know the atmosphere of the hospice, receiving a constructive task and longing for fellowship. Furthermore, this involves encountering the patient at the hospice with a desire to understand their needs. It also means being able to imagine what is filling the patient's thoughts and time, and how the encounter with the dying will affect the volunteers themselves. It will affect the volunteer personally, but it is his/her participation and experiences in the fellowship, together with the assignment he/she as a volunteer is given, which contribute to the meaning experienced.

According to Moore,<sup>26</sup> everybody has a need to identify with something, a desire to belong to a group.

But once you belong somewhere, the specifics of that place will also be of importance. Thus, fellowship is essential for hospice volunteers. Through their tasks in a hospice the volunteers can do something of significance for those they meet and care for. What the volunteers do and the appreciation they receive in return show them that they fill a function and have something to give, thus influencing the personal growth and maturity of the volunteer. Erikson,<sup>27</sup> calls it the integrity of the ego, where integrity stands for the ability to put different pieces together guided by a sense of relatedness and wholeness. In doing something for others there is hope and encouragement.<sup>28</sup> Suffering and alienation may arise if the volunteer's personal intentions cannot be fulfilled, in which case the individual can feel rejected. Accordingly, there is a need for the volunteer to be received in fellowship at the hospice. This need will be fulfilled when the volunteer feels affirmed as a caring person.<sup>29,30</sup>

## Discussion

Through volunteer narratives, this study reveals that the experience of being a volunteer to a large extent depends on how the volunteers are received into fellowship in the hospice and to what extent assignments are felt to be charitable and meaningful. Positive encounters with the hospice are closely related to personal growth. Volunteers feel rejected if their need for meaning and for belonging to the hospice is not satisfied. The meanings we have revealed show how important it is for hospices to embrace a comprehensive view of human relationships. Even a volunteer needs caring and comforting support.<sup>3,14,15</sup>

The limitations of this study need to be considered. Participants come from a country lacking a tradition of hospice volunteer services, and were sampled from only three hospices. However, in line with the phenomenological hermeneutical approach chosen, the study was not designed to present any extent of volunteers' experience but to illuminate its meaning. In this way, the results contribute to illustrate volunteer experience of a different kind to that dominating the literature from countries with well-developed programs for all aspects of voluntary work. This study shows that when tradition is lacking, there are key issues that can help volunteers to feel at ease in what they are doing. These key issues are: how the volunteer organization is structured and how the volunteers are personally affirmed. For example: the tasks that the hospice wants the volunteer to perform should be planned carefully together with each volunteer who needs information, guidance and support. This is in line with previous studies.<sup>2,5,6,10,12,31,32</sup>

The motives for being a volunteer can be external, such as having surplus time after retiring, as well as internal,

with an emphasis on the things that one has personally experienced. Trying to give meaning to one's own sufferings and vulnerabilities could be an example, or expressing gratitude for the help one receives through one's work. Both the assignment itself and reciprocal giving and receiving are included here. The volunteers' motivating force is to do well. However, this is not purely altruistic. It is also a matter of self-realization, where it is very important that the volunteer is affirmed in their work. Hence, volunteer work involves both 'me' and 'the other person'. In this way, their sense of meaning and continuity of life is strengthened.<sup>9,28-30</sup>

A natural part in any person's life is to care for and nurse other people,<sup>33</sup> and giving care is also a matter of receiving care.<sup>29,30</sup> Accordingly, in order to grow and mature as a human being, one needs to take part in caring relations. For hospice volunteers this can occur together with hospice personnel. The volunteers do not provide professional care but they offer, on a daily basis, an important social support built on friendship. Within this role, the volunteers are able to provide support and come up with ideas that the professionals cannot initiate due to the limitations of their roles.<sup>15,32</sup> The volunteers need to be welcomed into fellowship and offered the opportunity to share existential questions. Guidance and support can help the volunteers understand their values and sentiments in the face of death.<sup>8</sup>

Welcoming someone into a fellowship implies an endorsement of that person. Hagerty *et al.*,<sup>34</sup> describe how being approved as part of a fellowship is characterized by feelings of appreciation and importance and of an experience of fitting into that environment because they share in the core character of the work. Suffering follows if a person is not welcomed, especially when people arrive full of expectation. The majority of the participants exemplified this by the lack of information and support for the volunteers, resulting in uncertainty in how to perform tasks safely.

When professionals are hired, they begin their employment in the hospice with expectations. They need guidance and support to overcome the uneasiness of new circumstances and to be able to do a professional job.<sup>35</sup> Volunteers need guidance and support in corresponding areas. It helps the volunteer to feel '*I can manage it*' when meeting with the patient and it also creates feelings of identity with hospice.

Saunders,<sup>36</sup> is of the opinion that administration in a hospice should be flexible and accessible, prepared to bring volunteers and professionals together, each secure in their role. If the division of roles between professionals and volunteers is blurred and it is unclear which tasks are reserved for professionals only, then the volunteers will feel uncertain about what their proper place is.<sup>8,36</sup>

There is an idea that it is inappropriate to become a volunteer in a hospice if there has recently been a

personal bereavement. The reason behind this is a desire to avoid the risk of patients and professionals having to carry the burden of the volunteer's unsolved problems.<sup>4,37</sup>

Two of the volunteers in this study had begun as volunteers immediately after their relative had died in a hospice. Neither they, nor the respective hospices, found this to be a problem. These volunteers felt they had dealt with the sorrow during the period of sickness. Rather, our interpretations point to volunteers' need for guidance and support irrespective of time elapsed from previous separations.

The interviews conducted have highlighted significant issues in relation to the meaning of being a volunteer in a hospice. Some of the volunteers benefited from the request to share their story of being a hospice volunteer, as it helped them to understand their own experiences. The most profound question, however, remains unanswered. It was phrased by one of the volunteers in this way: 'Something takes place inside every person who passes through these doors.' Apparently, both the hospice and its patients touch the volunteers so deeply that it affects their lives. For this reason, we suggest further research along at least two different lines. Firstly, participant observations with an analysis of encounters between volunteers and patient, family, and staff. Secondly, biographical interviews probing significant experiences in the life of the volunteers, in order to increase the understanding of volunteering.

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