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ORIGINAL ARTICLE

# Exploring the Spiritual Dimensions of Indonesian Patients Living with a Permanent Stoma after Colorectal Cancer: A Phenomenological Study

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**Abstract**

**Background:** Research worldwide has highlighted the physical, psychological, social, and spiritual challenges faced by patients living with a permanent stoma following colorectal cancer. However, limited research has examined the spiritual dimensions of living with a stoma among Indonesian patients.
**Purpose:** This study aimed to explore the spiritual meanings and experiences of patients living with a permanent stoma due to colorectal cancer in Indonesia.
**Methods:** A qualitative phenomenological research design using Heidegger's interpretive phenomenological approach was employed. Fifteen participants who had been living with a permanent stoma following colorectal cancer for more than three months were purposively recruited, 12 of whom were Muslim. Data were collected at a national cancer hospital in Indonesia over nine months through in-depth, semi-structured interviews and analyzed using QSR NVivo 14 software.
**Results:** Three overarching themes emerged: (1) experiencing spiritual distress following cancer diagnosis and stoma formation (including rejection of life diversion, anger toward God, and social withdrawal); (2) embracing life with a stoma (including making peace with oneself and God, receiving social and professional support, and accepting the stoma); and (3) reconstructing self-existence after stoma formation (including developing meaning, hope, life goals, and pride in living with a stoma).
**Conclusion:** This study shows that spirituality helps Indonesian patients with colorectal cancer and a permanent stoma find meaning, achieve self-actualization, and make peace with themselves and God. Health professionals should anticipate these patients' spiritual needs through routine spiritual assessment and health education, and, when necessary, facilitate their participation in support groups to help meet those needs.

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## 1. Introduction

Stoma placement is one of the most common medical interventions for pathological conditions of the colon caused by colorectal cancer (Alenezi et al., 2022). Colorectal cancer patients undergo this placement for colostomy (6%-47%) and ileostomy (5%-69%) (de Almeida Silva et al., 2020). A survey reports that 120,000 people live with a stoma in the UK (Burch, 2017) and 100,000 people have the same condition in Germany (Ambe et al., 2018). In Indonesia, there are 6,205 ostomates due to colorectal cancer, who are predominantly male (59%), have undergone colostomy surgery (80%), and have a permanent stoma (69%) (Indonesian Ostomy Association, 2020). Data from stoma surgeries at the Dharmais Cancer Hospital, a national referral hospital for cancer diagnosis in Indonesia, indicate 162 cases of colostomy, 24 cases of ileostomy, and 16 cases of urostomy from 2018 to 2020, with an increasing number of permanent stomas (Andjarwati, 2022).

Recent studies indicate that a stoma causes physical, social, psychological, and spiritual distress, including disturbances in self-image, bowel patterns, sexual activity, and lifestyle,

affecting patients' quality of life (Alwi et al., 2018; Ambe et al., 2018; Ayaz-Alkaya, 2019; Näsvall et al., 2017; Yan et al., 2020). In Muslim-dominated communities, concerns about cleanliness have emerged as a barrier to living with a permanent stoma, leading some ostomates to avoid participation in prayers and fasting (Habib et al., 2020; Iqbal et al., 2016). In addition, a permanent stoma can interfere with marital relationships and the social status of ostomates (Golpazir-Sorkheh et al., 2022). Patients undergoing permanent colostomy experience traumatic events, must adapt to a new reality, and strive to improve their quality of life (Stavropoulou et al., 2021). The meaning of life for patients living with a stoma has therefore changed, and some report significant difficulty accepting this change. Uncertainty about the future is a challenge that some patients find comfort in religion, while others do not (Cipriano-Steffens et al., 2020).

Spirituality is an integral part of holistic care during disease progression (Nejat et al., 2017). It is the essence of life that energizes thoughts and actions (Taylor, 2002). It is associated with a patient's belief in something greater than oneself, a higher power, and something that provides meaning, mental strength, and a sense of peace, which can be achieved, for instance, through prayer, meditation, and interpretation of scripture (Cipriano-Steffens et al., 2020). Being able to adjust to the stoma and being highly spiritual have been shown to improve patients' quality of life (Vural & Sütsünbüloğlu, 2021). However, spirituality is often overlooked in clinical settings because it is an abstract concept, difficult to evaluate, and challenging to implement due to the busy schedules of medical staff (Puchalski et al., 2019). Nurses acknowledge the difficulty of discussing spirituality with patients, as it is not part of routine care and is not regularly addressed, and they lack confidence in discussing spirituality as a contributing factor to holistic, patient-centered cancer care (Zumstein-Shaha et al., 2020). Self-acceptance and adjustment to the stoma will improve well-being, and nursing care for ostomates will help them adopt healthy behaviors, engage in spiritual practices, and the need for existing transpersonal relationships (Rulino, 2022).

Several studies in Turkey, Iran, and Indonesia have shown that stoma placement affects patients' spirituality and well-being, but high spirituality may help them navigate difficult times, allowing them to accept and adjust to their condition (Alwi et al., 2018; Can Oz et al., 2022; Jaberi et al., 2019). While the clinical and practical aspects of stoma care are part of 'what can be seen' in the continuum of care, much of patients' spirituality remains unexplored. Globally, research has examined how a stoma affects the spirituality of Muslim ostomates, especially in worship and in maintaining a ritual 'pure' state *(thaharah)*. This certainly applies to Indonesia as well, where the majority of citizens are Muslims.

However, spirituality extends beyond the religious aspect. In Indonesia, where religion and faith are integral to culture, the changes brought by a permanent stoma and their implications for spiritual and social lives may carry different meanings. The researchers believe there is more to examine in Indonesian ostomates' spiritual landscape beyond the constraints of religion and changes in body image. The spiritual distress and well-being of colorectal cancer patients living with a permanent stoma have not been extensively studied in Indonesia. Thus, this study aimed to explore the in-depth spiritual experiences and meanings among colorectal cancer patients with a permanent stoma. The results are expected to deepen understanding of the phenomenon and support the implementation of holistic nursing care for patients living with a stoma.

## 2. Methods

### *2.1. Research design*

This study adopted an interpretive phenomenological approach in Heidegger's philosophical tradition. This approach enabled the study to investigate people's experiences and life meaning through Heidegger's Dasein lens (Dibley et al., 2020), aligning with the study's objective. This study used this approach to explore, interpret, and analyze experiences in depth, comprehensively, and systematically to identify the essence of spirituality among patients with a permanent stoma after colorectal cancer (Afiyanti & Rachmawati, 2014; Gill, 2020). The interpretive approach involved collecting, analyzing, and interpreting patients' perspectives and experiences living with a stoma. The researchers' interpretive understanding integrated insights from previous studies into the present research.

### *2.2. Setting and participants*

A purposive sampling approach was employed. Participants were intentionally selected based on their relevance to the phenomenon under study and their ability to provide detailed accounts

of their experiences of the spiritual aspects of living with a permanent stoma due to colorectal cancer. Participant recruitment was conducted at the outpatient unit of a national cancer hospital in Jakarta. The hospital was selected because, as a national referral center for cancer care, it receives patients from across Indonesia and at various stages of disease, facilitating effective and efficient participant recruitment.

Recruitment was conducted in collaboration with nurses and administrative staff during stoma bag collection. The inclusion criteria were as follows: (1) having been diagnosed with colorectal, colon, or rectal cancer; (2) having had a permanent stoma for at least three months, with the three-month period determined with reference to the transtheoretical model, thereby allowing participants sufficient time to adapt to and reflect on their experiences; (3) being able to communicate their experiences clearly; and (4) being an adult aged over 18 years. Fifteen participants were interviewed in this study. Data saturation was achieved when no new information relevant to the core spiritual aspects of living with a permanent stoma emerged from subsequent interviews.

### *2.3. Data collection*

Data collection was conducted through in-depth semi-structured interviews by the first author after each participant signed a research consent form. The interviewer is pursuing a postgraduate degree, has worked as a registered nurse at a different hospital for more than five years, and has no personal relationship with the participants. Participants determined the time and place of the interviews based on their comfort and to ensure their privacy. Eleven participants were interviewed at the hospital, while four were interviewed at their homes. The interviews were guided by an interview guide designed based on the literature (Cipriano-Steffens et al., 2020; Fisher, 2011; Jaberi et al., 2019) (Table 1). The interviews lasted between 35 and 90 minutes. All interviews were recorded with an audio recorder and transcribed verbatim. Fourteen participants were interviewed once, and one participant was interviewed twice to clarify data from the first interview. This did not affect the implications of the analysis. The second interview was conducted via a WhatsApp call. Face-to-face interviews were used at the early stage, with online interviews as follow-ups, to improve accessibility for participants, facilitate further data examination, and accommodate patients' health conditions and comfort. The online interview followed the interview guide to ensure data consistency. After the analysis was completed, participants were provided with a summary of the significant findings for validation as a member check to ensure the findings accurately reflected the spiritual aspects of self-existence in colorectal cancer patients with a permanent stoma.

**Table 1.** Interview guide

| Interview Questions |
|---|
| 1. Can you tell me what spirituality means to you? |
| 2. Can you tell me what life means to you since living with a stoma?<br>Probes:<br>- What did life mean to you before living with a stoma?<br>- How has this changed since living with a stoma?<br>- What does this change mean to you? Can you tell me more about it? |
| 3. Can you tell me about your current goals in life since living with a stoma?<br>Probes:<br>- What are your hopes or expectations for your life now?<br>- What does inner peace mean to you? Can you tell me more about it? |

### *2.4. Data analysis*

Data analysis followed a systematic process: all interview transcripts were read in full and then imported into NVivo for initial open coding by the primary researcher. Codes related to spiritual experiences were generated inductively from the data. The research team collaboratively reviewed code lists, discussed interpretations, and merged similar codes. Through an iterative process, potential themes were developed and refined, with consensus among researchers resolving any disagreements. Themes were finalized once they captured shared patterns and

reflected the complexity of participants' lived experiences. This analytic approach enhanced the rigor and transparency of theme development.

By following a Heideggerian interpretive path, the researchers moved through specific stages that shifted the focus from a medical condition to the participants' deep, lived experiences. This process involved "unfolding" the layers of how individuals existed in their daily lives. An interpretive phenomenological approach was appropriate because the study sought to examine how patients made sense of living with a stoma as part of their ongoing lives. In line with an interpretivist paradigm, this approach assumes that meanings are socially and contextually constructed and that participants' accounts provide insight into how a phenomenon is experienced and understood as lived (Mackey, 2005).

The analysis began with Fore-having, in which the researchers acknowledged their prior understanding and biases before engaging with the participants. This was followed by the Encounter with the Phenomenon, in which the researchers examined participants' "average everydayness"—the routine of life after a cancer diagnosis and before the stoma formation, when the body functioned as a "silent" partner. The next critical step involved identifying the Breakdown, the point at which stoma formation occurred and the body ceased to remain in the background and became a "conspicuous" object requiring constant attention. The researchers then looked for the Clearing, a metaphorical space in which participants' struggles revealed new understandings of their lives. At this stage, the analysis focused on Sorge (Care), particularly how participants' practices of cleaning and managing the stoma reflected a spiritual act of valuing their own existence. Finally, through the Hermeneutic circle, the researchers continually moved between the participants' specific words and the overall "big picture" of what it meant to be a human being confronting fragility (Benner, 1994; Crist & Tanner, 2003).

### *2.5. Trustworthiness*/rigor

Trustworthiness was established by addressing credibility, transferability, dependability, and confirmability. Data credibility was ensured by confirming participant narratives and addressing interpretive disagreement through member checking. During the analysis, the first researcher discussed the emerging categories and themes with other researchers who are experts in cancer and qualitative studies to provide perspectives and feedback. The transferability was enhanced by ensuring variation in the participants' characteristics and providing detailed information about the study context. The study location is a national referral center where patients from across the nation receive care. Therefore, the recruited participants exhibited variation in demographic characteristics, including age, gender, religion, educational level, marital status, occupation, treatment, and other factors. Data dependability was ensured through repeated consultations among the research team. The researchers responsible for data analysis each conducted an independent analysis, which was then compared and discussed to reduce subjectivity in data interpretation. Meanwhile, the confirmability of the data was ensured through peer debriefing, which aimed to reduce bias and uncertainty by consistently involving the research team throughout the research process. Moreover, an audit trail was maintained in NVivo software, and a reflexive diary documented the decision-making process throughout the data analysis.

### *2.6. Ethical considerations*

Ethical approval was obtained from the Research Ethics Committee of the National Cancer Hospital (Reference No. DP.04.03/11.7/018/2024). Participants received detailed information about the research procedures, and written informed consent was obtained from all participants before data collection. Participation was voluntary, with the right to withdraw at any time. Autonomy and privacy were maintained throughout the study. Researchers ensured that participants were free from discomfort, exploitation, and harm during interviews. Interviewers established rapport with participants before the interviews to ensure their comfort. Participant identities were anonymized, and only participant codes were used to maintain confidentiality.

## 3. Results

### *3.1. Characteristics of the participants*

Fifteen patients with colorectal cancer and a permanent stoma participated in the study, including ten males and five females, aged 35–75 years. Twelve participants were Muslim, two were Catholic, and one was Christian, representing diverse ethnic backgrounds. Their occupations

were also varied, including private employees, civil servants, teachers, traders, laborers, homemakers, and retirees. The duration of living with a permanent stoma ranged from three months to 12 years. Detailed participant characteristics are presented in Table 2.

**Table 2.** Characteristics of the participants (n = 15)

| Participant Code | Age | Gender | Religion | Ethnicity | Education | Occupation | Stoma Duration | Marital Status |
|---|---|---|---|---|---|---|---|---|
| P1 | 35 | Male | Islam | Sundanese | High School | Private Employee | 1 year | Married |
| P2 | 54 | Male | Islam | Betawi | Vocational High School | Retiree | 2 years | Married |
| P3 | 37 | Female | Islam | Betawi | High School | Private Employee | 1,5 years | Widowed |
| P4 | 54 | Male | Islam | Javanese | Diploma 4 | Civil Servant | 7 years | Married |
| P5 | 63 | Male | Islam | Javanese | High School | Retired Civil Servant | 1 year 10 months | Married |
| P6 | 69 | Female | Islam | Javanese | Elementary School | Laborer | 4 months | Widowed |
| P7 | 62 | Male | Islam | Javanese | High School | Retired Civil Servant | 5 years | Married |
| P8 | 43 | Male | Islam | Javanese | Middle School | Trader | 5 months | Married |
| P9 | 54 | Female | Islam | Javanese | Elementary School | Housewife | 3 months | Married |
| P10 | 53 | Male | Islam | Minangkabau | Master's Degree | Private Employee | 1 year 2 months | Married |
| P11 | 49 | Male | Islam | Sundanese | High School | Private Employee | 10 years 10 months | Married |
| P12 | 63 | Female | Islam | Betawi | Elementary School | Housewife | 4 years 11 months | Widowed |
| P13 | 75 | Female | Catholic | Chinese | High School | Housewife | 5 years | Married |
| P14 | 61 | Male | Christian | Javanese | Bachelor's Degree | Teacher | 12 years | Married |
| P15 | 60 | Male | Catholic | Betawi | Bachelor's Degree | Teacher | 3 years | Married |

*3.2. Spiritual experiences of colorectal cancer patients living with a permanent stoma*

In this study, three themes were identified during the analysis, each with corresponding categories (Figure 1). The first theme, spiritual distress from cancer diagnosis and stoma formation, emerged from three categories: rejection of life diversion, anger at God, and embarrassment and social withdrawal. The second theme, embracing life with the stoma, was generated from three categories: making peace with oneself and God, receiving support from healthcare professionals and significant others, and accepting the stoma. The third theme, reconstructing self-existence after living with a stoma, arose from two categories: developing meaning, hope, and life goals, and pride in living with a stoma. All these themes depicted the core dimensions of spirituality among colorectal cancer patients living with a permanent stoma.

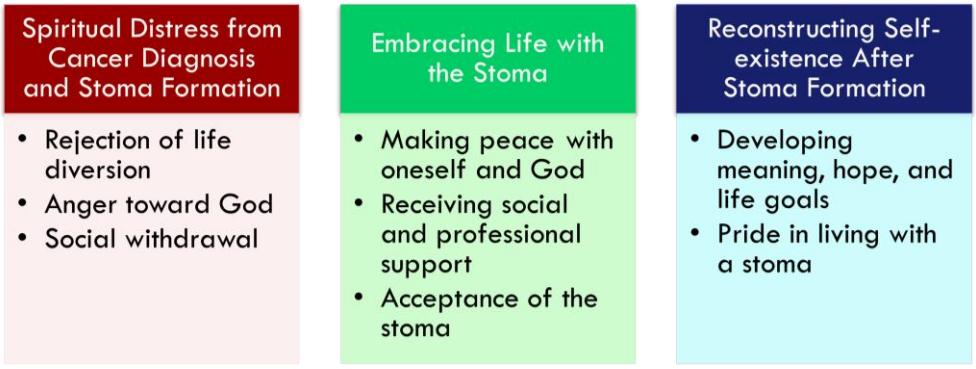


**Figure 1.** Themes and categories of spiritual experiences among colorectal cancer patients living with a permanent stoma

*3.2.1 Experiencing spiritual distress from cancer diagnosis and stoma formation*

Most participants experienced a grief response after cancer diagnosis and stoma surgery, starting with the rejection phase and followed by feeling angry at God, which triggered spiritual distress. The distress pulled the participants out of their social life as they felt embarrassed by their new condition with a stoma.

*3.2.1.1 Rejection of life diversion*

When the cancer diagnosis was revealed, all participants denied their condition. Physically, they suffered from severe cancer pain. Emotionally, they felt shock, despair, or a desire to die. Most participants expressed rejection of their life changes. Some participants expressed a desire to give up, as they reported a lack of information and encouragement from healthcare providers. This category also revealed emotional reactions that emerged during the depression phase, where participants experienced unstable moods, chaotic thoughts, and even doubts about their religious beliefs.

> *…the pain I experienced was excruciating. Even my wife and my son said that I was probably unconscious. That was the point where I was stiff, trembling, and couldn't scream anymore.* (P15, 60-year-old male)

> *At that time, I was desperate, but I hadn't given up yet. I didn't want to get treatment anymore. I didn't want to live.* (P4, 54-year-old male)

> *I had those thoughts three times: should I hang myself, should I drink rat poison, should I just go to the flyover? I wanted to run, but I was thinking, 'Will I die?'* (P11, 49-year-old male)

When the stoma was placed, the despair was evident in the new physical appearance and performance. Some participants suffered from limited activities that they could perform, and anxiety that, with an ostomy bag, they could not conduct worship and their work optimally. Two participants called themselves dysfunctional. P3 stated:

> *After the pouch was placed, I was in a period of turmoil. I was always angry and all sorts of things. …It's like there are so many trials for me.* (P3, 37-year-old female)

*3.2.1.2 Anger toward God*

Anger at God was a statement made by several participants who were still of productive working age when they first had their stomas placed. They expressed their feelings of injustice, as they felt that God was unfair in giving them cancer and a permanent stoma. They kept asking, "Why me?" "How many sins have I made compared to others?" They described how previously they blamed God, felt far from God, and considered their illness a punishment from God for their sins, as similar illnesses were not common in their community. They expressed that the dirty stoma bag made them feel unable to perform worship and other religious practices.

> *If this is really a punishment for me, at the time I thought it wasn't an illness; it was a punishment from God. What sin have I committed?* (P11, 49-year-old male).

> *My body was like this; I had a bag attached to it, and then, like, feces came out of my stomach. That was abnormal, and then I said there was no need for me to worship*. (P3, 37-year-old female).

*3.2.1.3 Social withdrawal*

The emergence of spiritual distress occurred when the colostomy bag was felt to interfere with participants' religious practices. They feared leakage from the ostomy bag, so they reduced their religious practices. The embarrassment caused by the sound of farts and the odor from the bag led them to avoid gatherings or congregating at the place of worship. Some participants said they were no longer fully active in community activities because their energy at that time was half

of what it had been before. Some had even withdrawn from their environment and eased their social interactions as they felt less perfect than others.

> *When I have long worship, I'm afraid of leaks. So I've reduced my religious activities*. (P7, 63-year-old male)

> *I feel insecure because I'm afraid of the sound of gas coming out; I'm afraid it will be heard by people who don't know my condition. The congregation isn't limited to one neighborhood community*. (P5, 63-year-old male)

*3.2.2 Embracing life with the stoma*

Stoma formation for Indonesian colorectal cancer patients was defined as the process of embracing the stoma into their lives. Spiritually, they perceived that a new lease on life had been granted by God, during which they were passing through a period of miracles, prayers, and support from their significant others. These guided them to accept the stoma as an integral part of themselves.

*3.2.2.1 Category 2.1: Making peace with oneself and God*

Participants expressed making peace with themselves by accepting their current condition and seeing their illness as part of themselves. They made peace with lingering anger to avoid constant frustration, which can be exhausting. They also made peace with pain, accepting it while maintaining a positive mindset, and some even practiced meditation to reduce their pain and manage their emotions. They developed peace with others, engaged in doing good for others, and prayed to God for their health. They decided to make peace with themselves, other people, and God.

> *…It will worsen my condition if I keep getting angry, so I decided to make peace with myself because, you know, it's hard to make peace with oneself. It takes a very long process. I used to be angry with God, refusing to pray or do anything. But then I thought, 'Yes, I need to make peace with myself…'* (P3, 37-year-old female)

> *Making peace with oneself means accepting that we now use a colostomy bag and recognizing it as part of our new life. Others can't do it, but we can, and we should be proud. I am proud to use a colostomy bag…* (P15, 60-year-old male)

Most participants expressed that their current life with a stoma is a second chance given by God. They stated that they were still given health and the opportunity to experience life again with a stoma permanently.

> *God still loves me; I'm still given a second chance at life because yesterday the cancer was spreading rapidly, and at the time I was in a brief stage that kept increasing, increasing, increasing*. (P1, 35 years old, male)

> *I am still very grateful because I am still being healed, still being given health again, and given the opportunity to live a second time. Why do I say the second time? Because at that time it was already fifty-fifty between life and death*. (P4, 54 years old, male)

*3.2.2.2 Receiving social and professional support*

Several participants perceived that their ability to be healthy and return to normal activities today was due to their belief in making various efforts to survive, such as attending scheduled check-ups. They believed that God had sent means through healthcare professionals to extend their lives, so they used them as best they could, especially since humans were God's perfect creation.

> *There are means; God has provided means. Those means I can use, I use them, so I can still recover, not because of the doctor but because of God. Because God has tools (to help us), and these tools are among us*. (P15, 60-year-old male)

In addition, some participants revealed that they have been able to survive healthily up to now because of prayers and support from their closest ones, who continually strengthen their lives. They believed they had to always be what their surrounding community hoped for, not complain, and view life as good karma, a reward from God through the prayers of those around them.

> *...the support of prayers is very powerful. Whether Muslim or Christian, if many people support you, the proof is in me; it's just a miracle. I believe it is just a miracle, not because of me, but because my friends all prayed to God.* (P14, 61-year-old male)

*3.2.2.3 Acceptance of the stoma*

Participants revealed that they treat their stoma as part of themselves, even giving it special and unique names like "magic bag." It is called a magic bag because it suddenly fills up without the participant's knowledge. Some also use the term FIFO (First In, First Out) for their stoma bag. This is evidenced by the participant's statements:

> *I accept that I must have this magic bag. The magic bag fills up without anyone knowing, so I always say this is my magic bag, not a stoma, but my magic bag right now.* (P15, 60-year-old male)

They reported that a stoma bag had not been inconvenient while on duty and that it strengthened their belief in God's presence, as it remained clean and did not leak feces during their duties. Additionally, they consistently communicate with it and maintain positive thoughts. They caress, pat, and greet the stoma as a manifestation of their spiritual connection, with one participant, P10, even stating that they caress it more than their wife. This demonstrates that ostomates are building a positive connection with the stoma and view the bag as part of themselves. This is evidenced by the following participant statements:

> *It increases our belief that Allah truly exists, so just believe that Allah hears our prayers. Alhamdulillah, the bag doesn't bother me; it's like Allah is giving me...* (P1, 35-year-old male)

> *Now, the first thing we love is our bag, not our wife. We caress the bag, check if it has contents; we rarely caress our wives...* (P10, 53-year-old male)

*3.2.3 Reconstructing self-existence after stoma formation*

The participants revealed their self-existence in relation to those around them, encompassing their relationship with others. They developed greater self-awareness of their meaning, hope, and goals in life and achieved self-actualization by taking pride in being a person living with a stoma. Moreover, they successfully dealt with their life diversion, others, and God.

*3.2.3.1 Developing meaning, hope, and life goals*

Participants expressed a deeper understanding of themselves through the meaning, hope, and life goals they hold. These elements embodied their sense of purpose and desires. Most participants, after having a stoma installed, shared similar goals and hopes: to regain health, prolong their lives, and enhance their worship. However, one participant who had the stoma installed three months earlier was still undergoing therapy and had not been informed about the stoma's permanence. Thus, she still hoped to recover normal bowel function. Here are the supporting statements from participants:

> *Life means that I can still provide for my family. From the beginning, that's been my prayer, 'Please Allah, grant me healing, as many are still relying on me.'* (P4, 54-year-old male)

> *My only hope is that if I'm called, I'm ready. I surrender to God. My prayer is for health and a long life. Whenever I pray, that's what I ask for.* (P14, 61-year-old male)

Living with a stoma is perceived as adopting a new lifestyle, new patterns of living, and even as being reborn as a new person with a new will, making changes in life. P15 stated:

> *...don't be ashamed because this is our new lifestyle. The lifestyle that not everyone has. Sometimes people say it's crazy to carry a toilet in front of me, but I don't feel annoyed.* (P15, 60 years old, male)

*3.2.3.2 Pride in living with a stoma*

Participants demonstrated their capabilities despite their illness, ensuring they were not perceived as incapable by those around them because of their stoma. Additionally, several participants expressed self-love by considering their illness part of themselves or by becoming friends with it. They talked to themselves and were not ashamed of their condition as an ostomate; they even took pride in living with a stoma and found satisfaction in their long life as a cancer survivor. This sense of satisfaction and pride in their current condition enables them to achieve more than healthy individuals, even performing religious duties and obligations. Some participants expressed that they could still benefit those around them, such as one participant who woke the community for sahur (eating before fasting) every day. Some examples of statements about self-actualization are as follows:

> *I'm actually proud to be a person with a stoma. I'm seriously saying this; I am a person without a bowel opening. I use a magic bag; my bowel movements go through my abdominal wall. Why are you proud? Yes, because not everyone can be as strong as me.* (P15, 60-year-old male)

> *Alhamdulillah, I can still serve as an imam at the mosque. I have been an imam up to now, but sometimes, if there is no ustadz (religious teacher), we serve as backups. I am still trusted, so I feel this is one way I can be beneficial to others... (P7, 62-year-old male).*

## 4. Discussion

This qualitative study highlights that the spirituality of colorectal cancer patients has evolved from a grieving phase—when they rejected the cancer diagnosis and the stoma—to a stage of self-actualization—when they integrated the stoma into their lives and saw it as part of their personal, social, and spiritual lives. Over time, they embraced life with the stoma by developing a close relationship with it and recognizing it as part of themselves. This friendship transformed their hatred of the life diversion into a process of self-acceptance, which begins with self-awareness—understanding one's internal state, preferences, resources, and intuition. By attending to relevant personal experiences, they increased self-awareness and clarity about themselves. Self-acceptance entails being open with oneself and avoiding denial or avoidance (Klussman et al., 2022). Creating a stoma is seen as an opportunity to continue living and to strengthen this friendship (Silva et al., 2017), as it necessitates a new way of living due to significant changes in daily life (Souza Andrade et al., 2016).

*4.1 Experiencing spiritual distress following cancer diagnosis and stoma formation*

This study found that participants experienced spiritual distress due to the cancer diagnosis and stoma formation. Spiritual distress is defined as a state of suffering associated with an impediment to integrating the meaning of life through relationships with oneself, the world, or the Divine (Herdman et al., 2021). The distress was expressed as rejection of the life diversion, anger at God, and withdrawal from social activities due to perceived embarrassment. For Muslim participants, the distress was also influenced by the act of worship. In Islam, the concept of najis refers to substances considered ritually impure that must be cleansed before certain acts of worship, particularly shalat (prayer). In addition, the concept of thaharah refers to a state of ritual purity or cleanliness required for the validity of worship. In patients with an ostomy, the uncontrolled passage of feces or urine through the stoma caused concern and fear. This was deeply associated with a perceived loss of the ability to fulfill their role as a devout Muslim. As a result, an existential crisis may be triggered, in which the individual's sense of self-worth, life purpose, and relationship with God are questioned due to the illness. This aligns with "demoralization syndrome," which manifests as feelings of hopelessness, incompetence, dependence, burden, loss of meaning, and existential distress at a cancer diagnosis (Lazar et al., 2025).

The permanent physical change from stoma formation created a diversion in patients' lives. A permanent stoma caused inconvenience in daily life, altered hygiene routines, persistent fear of

leakage or odor in public, pain, and sleep disturbances (Latifee et al., 2025). This led patients to reject the life changes at the beginning of stoma formation. Adequate education and support in adopting healthy coping mechanisms are needed to help patients come to terms with the permanent stoma and integrate this change into their daily life.

### *4.2 Embracing life with a stoma*

This study found that adapting to a bodily change and a new lifestyle is perceived as a second chance to survive and act independently until life feels normal again, with the stoma being accepted as part of oneself. This finding aligns with a meta-synthesis study in Spain, which described the lives of patients with stomas using the Triple-A model (Acceptance, Adaptation, Autonomy) and identified spirituality as a strategy for coping with difficult situations throughout their lives (Capilla-Díaz et al., 2019). This process also aligns with the adjustment to life with a stoma in an Indonesian study of CRC survivors with stomas, under the theme of achieving self-reconciliation, with subthemes including seeing the stoma as a lifesaver, accepting the stoma, and building confidence as an ostomate (Afiyanti et al., 2023).

Patients with stomas in this study integrated the presence of the stoma into their lives and maintained it through acceptance, adaptation, and adjustment. Gratitude as an expression of self-acceptance in this study was manifested as being given a second chance at life, with an emphasis placed on the relationship with God as a manifestation of happiness, thankfulness, and appreciation for achievements in life due to God, others, and the surrounding environment. Positive actions were encouraged as a form of self-acceptance with a stoma. This was also revealed in an Indonesian study, in which gratitude was conceptualized as three components: appreciation, positive feelings, and expressions of gratitude (Listiyandini et al., 2017). Given a new chance at life with a new lifestyle, patients had to learn to sustain life with a stoma and felt fortunate with their current life and new opportunities. This appreciative perspective reflected the patients' gratitude to the Divine and to life. Thus, this allowed patients to foster positive feelings towards a new lifestyle with a stoma. This opportunity was to be used optimally by adapting to return to a normal life, similar to life before having a stoma (McGeechan et al., 2022). Learning to adapt to the stoma and striving to normalize life were efforts made to return to a normal life, especially within the theme of social self for adolescents (Mohr & Hamilton, 2016).

The stoma was considered part of oneself, supported by findings in which names were given to the stoma as an expression of making it part of oneself. Naming the stoma was a form of accepting its presence as integrated into oneself, even creating new meanings and assigning oneself the role of educating the stoma by talking and communicating with it (Afiyanti et al., 2023). It could be viewed as ostomates making the most of their situation as an expression of gratitude for their second chance in life. Communication with the stoma was seen as treating it as part of oneself, which is essential for conversation and communication, fostering a positive mindset and helping one feel that the stoma was not troublesome and could be trained.

### *4.3 Reconstructing self-existence after stoma formation*

This study suggests that self-existence, defined as the way individuals actualize themselves and their potential, thereby making their existence meaningful (Fitriawati & Retnasary, 2018), arises when ostomates get to know themselves better and find meaning, hope, life goals, and self-actualization. In the spiritual concept, self-existence refers to one's presence in the world and state, involving the exploration and understanding of the meaning of life, values, beliefs, and personal goals (Cobb et al., 2012). Abraham Maslow stated that recognition of existence was the highest human need, far surpassing the need for safety, clothing, food, and shelter (Adziima, 2022). For colorectal cancer patients with a permanent stoma, interaction in finding self-existence, a spiritual aspect, was conducted by developing care and trying to understand the importance of spirituality, thus connecting interactions by embracing the spirit in giving meaning to oneself and those around, providing a picture of who I am, what my hopes and life goals are, and feeling a sense of satisfaction and pride (Costello, 2018). This finding was relevant to studies affirming that having goals to achieve after a stoma installation was identified (Alwi et al., 2018). Findings in Iran indicated that one aspect of existence was the search for life's meaning (Jaberi et al., 2019). In a study of the elderly in Turkey, two themes of life's meaning were identified: love and family, and helping and compassion, which provided strength. The theme of spiritual function in relation to God involved more profound prayer and trust in God (Can Oz et al., 2022).

This theme showed that younger individuals were often found to have greater self-existence and a more meaningful life, and that colorectal cancer patients with permanent stomas were found to have achieved inner peace. Inner peace was considered individual and was attained by making peace with oneself, with others, and with God. In addition to inner peace, permanent colorectal cancer patients were found to have discovered meaning in their lives, seeing themselves as still significant to their family and surroundings, with goals and hopes to remain healthy and motivation to fight their illness despite having a stoma for life. Satisfaction, pride, and the ability to benefit others were also found to be attained. A sense of responsibility was also observed, especially among colorectal cancer patients who were family breadwinners. Relevant hopes and goals were aligned with studies that identified themes of goals to be achieved after a stoma installation (Alwi et al., 2018). Studies on existence were found to help view life as more meaningful and coherent and were seen as a new life for women with breast cancer (Devi & Fong, 2019), which was found to be relevant to the findings in this research.

The search for meaning is recognized as a spiritual phenomenon in nursing, where meaning or purpose is often connected to a sense of being called by destiny or fate. The discovery of life's meaning, purpose, and hope, as well as a deeper understanding of oneself, was found in this research. The presence of life's meaning, purpose, and hope led to behavioral changes towards improvement and greater acceptance of oneself as an ostomate with specific goals and hopes. This was consistent with findings from studies in Iran, in which the search for meaning was identified as a characteristic of spiritual health (Jaberi et al., 2019; Cheng et al., 2024). This was also explained in the study by Hatamipour et al. (2015), which found themes of seeking peace and finding the meaning and purpose of life, including acceptance of reality, searching for meaning, having a meaningful end, and transforming the meaning of life.

A sense of responsibility, which is also part of the spiritual concept of self-existence, was still felt by colorectal cancer patients with permanent stomas, as found in this research. Responsibility for families was maintained, with efforts made to bring happiness, provide for the family and children, and ensure their livelihood. This was commonly observed among individuals under 60 years of age, both male and female, even though some had withdrawn from their permanent jobs, but continued to have a sense of responsibility towards their families. This contrasted with the findings of Shin and Lee (2022), where a study on female patients undergoing iodine therapy found a theme of avoiding those around them due to concerns about close contact with their children, driven by a greater sense of responsibility for child-rearing compared to men, and fear of exposing children to radiation.

Knowing oneself better, having goals, and hoping for good health and a long life to benefit the family were highlighted. This was aligned with studies showing themes of behavioral changes and goal-setting for recovery (McGeechan et al., 2022) and themes of having hope (Khosravani & Nejat, 2022). The impact of a stoma on social life was found to increase emotional and cognitive responses, especially among younger individuals (Ayaz-Alkaya, 2019). Colorectal cancer patients in their productive years, who were the primary earners for their families, were found to derive their self-worth from providing for their families. Thus, the new condition, with decreased ability to work and reduced income, led to diminished self-worth and a sense of being less meaningful. Men were found to feel a loss of masculinity when they could no longer contribute economically to the family, as work was considered a framework for forming male identity (Capilla-Díaz et al., 2019). Furthermore, findings in this theme indicated that older age was more strongly associated with improving religious practices and drawing closer to God. This was relevant to studies conducted on the elderly in Turkey, where two themes of life's meaning were identified: love and family, and helping and compassion, providing strength, with a deeper focus on spiritual function and relationship with God through prayer and trust (Can Oz et al., 2022).

Pride and a sense of peace within the theme of proving self-existence due to having a stoma, as found in this research, were shown to enhance the perception of a valuable life for those with a stoma and for those around them. This sense of value was found to be meaningful in the individual's relationship with themselves and others. This was relevant to a study in Thailand, where themes of feeling that life is valuable, being satisfied, and finding peace with oneself and others were identified (Phenwan et al., 2019). Additionally, appreciating other aspects of life post-stoma was highlighted, as described in the study by Capilla-Díaz et al. (2019), which stated that patients with a stoma must accept their new reality, recognizing that anger would only worsen the situation and that satisfaction and pride must be present within themselves. Another supporting

finding was from a study in Sweden, which identified a theme of believing that the stoma brought positive changes to their lives, with the stoma being seen as a symbol of survival from cancer and something to be proud of (Näverlo et al., 2023). These findings suggest that pride in living with a stoma may reflect a positive reconstruction of self-existence, in which the stoma is no longer perceived solely as a source of loss but also as a meaningful part of survival and continued life.

## 5. Implications and limitations

The findings of this study can be used by nurses in their practice to enhance understanding of patients' experiences and of self-existence as a spiritual aspect related to themselves, others, and their environment. Insights gained from this study may assist nurses in appreciating and conducting the necessary assessments that can be shared with other patients. By doing so, nurses can gain greater confidence in supporting stoma patients as they navigate the process of accepting the stoma as part of themselves. This understanding also highlights the importance of recognizing patients' need for social and emotional support in sustaining life. Furthermore, nurses can offer practical guidance to encourage hope, set life goals, and foster a sense of meaning in life despite the challenges of living with a stoma. In this way, self-esteem can be strengthened, and peace with oneself, others, and God can be nurtured as vital sources of resilience.

The limitations of this study primarily include the single data-collection site. Since the data were collected exclusively at one hospital in Jakarta, the findings represent only the unique social, institutional, and cultural context of this site. Consequently, the results may not be fully transferable to other sites with different cultural contexts and organizational structures. A single geographic location may also limit the diversity of perspectives and experience captured by this study, resulting in a homogeneous participant pool and site-specific bias. Despite this limitation, efforts were made to remain consistent with the research objectives, ensuring the credibility and relevance of the findings. Future studies could include participants from multiple healthcare settings and different cultural contexts to capture a broader range of experiences. Further research is also needed to explore how self-existence and spirituality evolve across different stages of adaptation to living with a permanent stoma.

## 6. Conclusion

This study's findings showed that colorectal cancer patients living with permanent stomas experienced spirituality through a process of spiritual distress, embracing life with the stoma, and reconstructing self-existence. Through this process, patients constructed meaning in life through the spiritual dimension of self-existence, grounded in their goals and hopes. Their ability to develop self-appreciation was demonstrated by a sense of pride in living with a stoma, accompanied by inner peace through reconciliation with themselves, others, and God. This process of reconciliation emerged as an important source of resilience, strengthening their capacity to endure the challenges of living with a stoma and shaping their relationships with God, the self, others, and the broader environment.

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## Author contribution

DAR and YA: Conception and design of the study, data acquisition, and data analysis and interpretation; DJ and HP: Drafting the manuscript and critically revising it for important intellectual content; DAR, YA, DJ, and HP: Final approval of the version to be published and accountability for all aspects of the work.

## Conflict of interest

No conflicts of interest were reported in this study.

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**Declaration of Use of AI in Scientific Writing**

The authors used AI tools (Grammarly) solely to check grammar, improve language clarity, and ensure consistency in writing. The use of AI was limited to linguistic refinement and did not contribute to the development of ideas, data analysis, or the substantive content of this work.

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