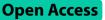
## RESEARCH



## Oncologists' palliative care referral behaviour: testing utility of social exchange theory as an explanatory framework



Naveen Salins<sup>1\*</sup>, Sean Hughes<sup>2</sup> and Nancy Preston<sup>2</sup>

## Abstract

**Background** Adults and children with cancer are referred to palliative care infrequently or late. Oncologists often gatekeep these referrals. Social exchange theory is used to explain physician referral behaviour in various clinical settings. Its utility in a cancer palliative care setting is not known.

**Methods** We used Karl Popper's hypothetico-deductive approach to test the hypothesis. The hypothesis was that social exchange theory is a helpful framework for explaining oncologists' palliative care referral behaviour in a cancer setting. The utility of the theoretical framework was tested against the empiric findings of a systematic review and original research.

**Results** Most components of social exchange theory known to explain physician referral behaviour like beliefs about the provider or service, emotions triggered during the professional engagement, its symbolism and stigma, the complexity of the referral task, efforts needed to achieve it, its cost, benefit, and value were similar in a cancer setting. Empirical findings suggest that oncologists provided strategies and solutions to better palliative care integration instead of comparing their existing engagement with potential alternatives and choosing them.

**Conclusion** Social exchange theory was found to be helpful in explaining oncologists' palliative care referral behaviour. To further develop the social exchange theory based on the data used to test it, it is recommended to include feedback and solutions as a component of the theoretical framework alongside a comparison level for alternatives.

Keywords Oncologists, Palliative care, Referral, Behaviour, Social exchange theory

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## Introduction

People of all ages with cancer worldwide are not referred to palliative care as often as they should be, and the referrals that do occur happen very late in the patient's life [1-6]. This problem is even more pronounced in lowmiddle-income countries [7-12]. Due to the higher cure potential in a paediatric oncology setting, many children with cancer only receive palliative care in the very last days of their lives [2, 4, 13, 14]. A systematic review showed that, internationally, the median time between palliative

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care referral and death is only 19 days [15]. Many children with cancer who need palliative care don't have access to it [16, 17]. Patients often continue receiving cancer treatments until the end, which can impede symptom management and end-of-life care. [4, 5, 14, 18]. Delayed palliative care referrals often hinder communication and shared decision-making processes [3, 19, 20] and may also lead to unnecessary invasive medical interventions at the end of life [5, 21] and increased in-hospital deaths [4, 5, 21, 22].

A wide range of factors might influence healthcare professionals' behaviours, decision-making and clinical practice [23]. Theory-driven approaches are often used to understand and predict clinicians' behaviour in healthcare [24]. The social exchange theory has been used to explain physician referral behaviour in various healthcare settings [25–29]. However, its usefulness in a cancer palliative care setting is not known. In this study, we explored the utility of social exchange theory as an explanatory framework to describe oncologists' palliative care referral behaviour to hospital-based specialist palliative care teams in a cancer care setting.

#### Methods

Our hypothesis was that social exchange theory is a helpful framework for explaining oncologists' palliative care referral behaviour in a cancer setting, and the hypothetico-deductive method was used to test this contention. [30]. The hypothetico-deductive approach enables the exploration of how data contributes to testing a hypothesis and its role in confirming or undermining it [30]. Furthermore, it formalises and demonstrates the relationship between the hypothesis and the data [30]. In a hypothetico-deductive method, an established theoretical framework is tested against the data collected through observations [31]. Using empirical evidence allows for testing, modifying, and rejecting a theoretical framework [32]. The premise of Karl Popper's scientific philosophy is that all dogmas and theories should be tested and cautioned against their uncritical adoption [33]. Furthermore, the researchers are confronted with data that needs explanation. Testable hypotheses are deduced from existing theories, and scientific data can be used to test a hypothesis. Confirmed hypotheses are kept or modified, and falsified ones are rejected [34]. Therefore, we chose Popper's hypothetico-deductive method for our scientific inquiry. Karl Popper's hypothetico-deductive approach has seven steps, detailed in the next section [35].

#### Results

## Step 1: Identifying a broad problem area Broad problem area: Timely palliative care referral in a cancer setting

Research has shown that both adults and children benefit from timely referral. It improved quality of life, enhanced symptom control, bettered communication, informed treatment decision-making, advance care planning, endof-life care, and reduced costs [36-41]. In a cancer care setting, oncologists may act as gatekeepers, and their gatekeeping behaviour can either help or impede referrals to palliative care [42, 43]. Studies have indicated that gatekeeping behaviours may involve delaying a referral for palliative care until the end of a potentially curative treatment or only making a referral when explicitly requested by the patient's family [44-46]. Additionally, it has been revealed that oncologists prefer controlling and coordinating the care process of their patients at every stage of their illness trajectories, including the referral process [47-52]. Therefore, it's essential to comprehend oncologists' referral behaviour in a cancer setting to improve engagement and early integration of services.

## Step 2: Defining a problem statement Problem statement: Referral behaviour of oncologists underpins timely palliative care referrals

This research focused on the significance of timely referrals for palliative care and how oncologists' behaviour affects this process. It considers the social and cultural context and all stakeholders' viewpoints on healthcare referrals [43]. Understanding their perspectives on what promotes or impedes referrals can inform changes in policies and practices that have the potential to address health disparities and bring about transformative improvements [53]. In some healthcare settings, social exchange theory has been used before to explain how physicians make referrals [25-29]. These studies showed a strong correlation between referral exchange behaviour and the principles of social exchange theory, which is described in Table 1. However, none of these studies was conducted in a cancer care setting. In this study, we tested the utility of social exchange theory as a framework for explaining oncologists' referral behaviour in a cancer palliative care setting using a systematic review [54] and original research [55] conducted by the authors of this paper.

#### Step 3: Develop a hypothesis

## Hypothesis: Social exchange theory is useful for explaining oncologists' palliative care referral behaviour in a cancer setting

Referring patients in a healthcare setting is a form of social interaction that involves sharing responsibility for patient care between the referrer and referee, which can be explained through social exchange behaviour [28, 29]. Social exchange theory explains how people's social behaviour is influenced by the possibility of gaining or losing something of value through an exchange [56]. Social interactions are usually seen as a means for individuals to fulfil their needs, seek rewards and avoid costs

#### Table 1 Components of Social Exchange Theory

SI.

No 1

2

3

4

5

6

8

Component

Sentiment

Task

Interaction

| Description  |
|--|
| Sentiments are the views and attitudes of one social actor towards another involved in the exchange [57]. Presuppositions, power and motivation are the common social exchange sentiments [58]. Presuppositions are a preformed notion about the exchange or the persons involved in the exchange based on previous experiences, knowledge or biases [58]. Power in social exchange is linked to the social actor's virtues in the society or situation and depends upon another person's dependency on the social actor [59]. Therefore, it creates a power dependency relationship [59]. Motivation is the desire of the social actor to achieve something of value that is closely associated with the satisfaction of achieving it [60]. |
| The task corresponds to the effort required to achieve an activity. Structural and contextual conditions determine the efforts needed to accomplish the task [61]. Moreover, emotions triggered by the task activities also determine the person's involvement in the task [57]. Therefore, the jointness of exchange does not only depends upon the reward of the exchange but also on the structural and contextual conditions constraining or enabling the task and the emotions triggered by it [57].  |
| Interaction relates to the process of exchange [58]. There are three kinds of exchange. The trade exchange is purely in terms of economic gains and losses, and the power exchange is hierarchical, where there is limited choice and freedom to the persons participating in the exchange [58]. As the act of referral is a social behaviour [29], in this research, I am focusing on   |

|        | persons participating in the exchange [58]. As the act of referral is a social behaviour [29], in this research, I am focusing on |
|--------|---|
|        | the behavioural exchange, where the relationships are voluntary and interdependent, and behaviours act as tendencies in           |
|        | the exchange process [60]. The person participating in the exchange takes into account the task, reward and cost of inter-        |
|        | acting and will continue to interact if the interaction is in alignment with the person's expected outcomes [60].                 |
| Reward | The rewards are the benefits of exchange. In the social exchange, rewards are discussed in terms of a person's gains and its      |
|        | influence on the exchange process [62, 63]. There are several dimensions to the reward. Immediate rewards are based on            |
|        | the behavioural choices associated with a single event or an outcome. In contrast, long-term rewards are relational rewards       |
|        |   |

based on the long-term association of social actors and cumulative outcomes of interaction [60]. Anticipatory rewards are the potential future rewards expected by the person in the exchange process [60]. Rewards are a form of reinforcement, and social relationships cease to exist unless the exchange reinforces the person's expectations [56]. Cost Cost in social exchange corresponds to the negative effects or losses sustained during achieving the reward [59, 62]. When

costs involved in achieving the reward are high, then there is less chance of a person taking up the task [59]. The person's decision to choose an activity, forego it or choose an alternative depends upon the costs associated with it [59]. Profit Profit relates to a person's expectation of rewards and the costs incurred in the process. Moreover, in a social exchange, the

proportion of rewards to the costs should be a fair process [59, 62]. 7 Value means not just the assessment of profit due to interaction but the feelings of satisfaction achieved by doing that Value activity [58]. The value associated with doing an activity and the sentiments the person gets from another person during

the process of activity determines the long-term association with the activity [58]. The person continues to do the activity even if the activity does not bring profit if it provides satisfaction and adds value [60]. Comparison level is the standard against which the social actor measures the utility of the rewards [64]. The standard could Comparison

l evel be based on the previous or current experience of rewards and alternate choices that are available [64]. This perception is based not just on the magnitude of immediate rewards but also on the cumulative slope of the reward [58]. Therefore, one activity or an outcome of a single palliative referral is unlikely to make a person choose an alternative or influence the referral behaviour [58]. If the cumulative perception is negative and an alternative is more profitable, then the person may choose to terminate the relationship and choose the alternative [58, 64].

[56]. The components included in the social exchange process are detailed in Table 1.

## Steps 4,5 and 6: Determining measures for hypothesis testing, data collection and analysis

Measures for hypothesis testing, data collection and analysis The hypothesis was tested using a systematic review [54] and original research [55] conducted by the authors of this paper. The data collection and analysis of these two measures are described below.

We conducted a systematic review [54] to answer the question: "What do oncologists and haematologists think about referring patients to palliative care?" We looked at studies published in English that involved human subjects from January 1, 1990, to December 31, 2019. The studies we included focused on the opinions of oncologists, haematologists, and cancer specialists regarding referring patients to palliative care in a cancer care setting. To ensure review quality, we assessed the methodological rigour of all studies using Hawker's tool [57]. Only studies with a score of 19 or higher were included. Two reviewers independently conducted screening, quality appraisal, and data extraction. This review used various evidence, including surveys and qualitative and mixed-method studies. We chose Popay's narrative synthesis to analyse study findings, ideal for identifying common themes from textual data gathered through surveys and qualitative studies [58]. Furthermore, Popay's method enables using a theoretical framework for interpreting study findings [58]. After reviewing a database of 9336 citations, we found 23 relevant studies for our synthesis. Through this process, we developed five themes related to presuppositions held by oncologists and haematologists, power dynamics and trust issues, challenges in making a palliative care referral, weighing the costs and benefits of a

referral, and strategies to facilitate the referral process [54].

A qualitative study [55] was conducted to study the views of cancer specialists on aspects that either support or impede palliative care referral in paediatric oncology. We recruited 22 oncologists and haematologists who manage children with cancer from 13 tertiary cancer centres. We chose these centres based on three criteria: they offer paediatric oncology and haematology services, they have oncologists and haematologists who manage children with cancer, and they provide palliative care services. We gathered research data through individual face-to-face semi-structured qualitative interviews and analysed the data using Braun and Clarke's Reflexive Thematic Analysis method [59]. Through data analysis, we have generated four key themes: attitudes and ideas regarding palliative care and referrals, the steps involved in referring a patient to palliative care, assessing the advantages and disadvantages of referral, and creating successful approaches for incorporating palliative care into paediatric oncology [55].

#### Step 7.1: Data interpretation and theory evaluation

The findings of the systematic review [54] and the original research [55] were used to test the hypothesis; the data was interpreted using the social exchange theory.

#### Human cognition and emotions

Human cognition is an essential motivation for social exchange that goes beyond the process or outcome of the exchange [60]. The social actors are emotive and cognising, and the emotions experienced by the social actors act as an internal reinforcement for the exchange behaviour [61]. However, sentiments go beyond emotions, representing an affective state or feeling where emotions are linked to a social object or social unit [62]. It is a social construct that leads to an affective response, which is the psychological state of the social actor [63]. The presupposition is an implicit assumption or belief about a phenomenon [64]. Presuppositions trigger cognitive responses that impact decision-making and social behaviour [65].

Oncologists hold certain beliefs about the reliability of palliative care providers, as shown in both review and research studies [54, 55]. Trust is a cognitive process that involves one person expecting another to be trustworthy [66]. Trustworthiness is believing in someone's ability, reliability, integrity, resourcefulness, and benevolence [67]. In both review and research findings, oncologists emphasised the importance of competence-based trust when referring patients to another person or team for effective task performance [68].

The study [55] brought out benevolence as a facet of trustworthiness. Being benevolent means doing good and

being kind. [69]. In the study [55], oncologists felt that some palliative care providers were less benevolent due to a perceived lack of empathy and a lacklustre approach. The study [55] noted that social actors' identities impact trustworthiness, cognition, and exchange behaviour [62].

In the review [54], oncologists reported feeling confident in their ability to provide care. However, the study [55] found that many oncologists had mixed feelings about their ability to respond to these needs appropriately. Perceived self-efficacy refers to a person's belief in their ability to perform a task to meet their and others' expectations [70]. This belief impacts cognitive and emotional processes, social behaviour and actions [70]. The study [55] found that only a few oncologists felt confident providing palliative care. Most acknowledged the benefits of referring patients to palliative care but recognised their limitations in providing these services due to a lack of skills and knowledge. This awareness of their limitations and self-efficacy influenced their referral behaviours.

Emotions triggered by task activities are central to social exchange behaviour [61]. The exchange process can trigger a host of emotions. Some are general feelings like pleasure or dissatisfaction, while others are specific feelings like anger, shame, trust, confidence, gratitude or pride [71]. The exchange outcomes also produce emotions that influence the social actor's commitment to the exchange process [71]. A positive emotion triggered will encourage the social actor to repeat the experience, whereas a negative emotion may deter future participation in the exchange process [71].

The review found that [54] some oncologists experienced negative emotions such as therapeutic failure, abandonment, and a break in the therapeutic relationship when referring patients to palliative care. It could also lead to a loss of hope and hinder future engagement. On the other hand, the study [55] found that positive feedback from families about the quality of palliative care services was seen as a reinforcement for future referrals by oncologists.

#### Power, status and expectations

In social exchange, the social actor making the referral retains the reward power, whereas another social actor is rewarded with the referral if they meet the expectations of the referrer [72]. In the study [55], oncologists made a referral to palliative care if those services met referrer expectations and agreed with the line of management advised by referring oncologists. This one-sided dependency leads to asymmetrical relationships where the person receiving the referral must comply with the person's wishes for making the referral [72]. and can lead to coercive power, in which a social actor obtains compliance from another [72]. This phenomenon was observed in our review [54] and research [55] findings. The

oncologists wanted to oversee and manage the patient's care throughout the illness, even when palliative care providers were involved. They desired to maintain control over the patient. It is an example of a social actor using their status or superior attributes to command compliance. [73].

Expert power is where the social actor believes they have expert skills and knowledge in a domain not possessed by another social actor, and legitimate power is derived from the virtue of their position [74]. According to our study [55], oncologists' qualifications and experience influenced their decisions to refer patients. Due to their training, oncologists believed they were more qualified and experienced than palliative care providers. They also felt they had the authority to control and coordinate all referral activities [63]. The review supported the study findings [54], which showed that oncologists had the power to control the referral process and saw palliative care referral as interference in their care process, leading them to gatekeep the process.

#### Symbolism and stigma

Exchange behaviour also has a symbolic perspective where social actors interact and communicate about a phenomenon using symbolic inferences [63]. In the review [54], oncologists believed that referring patients to palliative care signified a loss of hope, a disconnection in the therapeutic relationship, and abandonment. In the study [55], oncologists compared the relationship between themselves and their patients to that of a family. They saw palliative care referral as equivalent to handing a family member to someone else, indicating a failure in treatment and letting down the patient. Oncologists also observed that families saw palliative care referral as an indication of a change in the patient's condition, a shift in treatment goals, or the possibility that the patient may not recover.

Stigma is a complex phenomenon characterised by stereotypes, prejudices and discrimination [75]. In the study [55] and review [54] findings, Oncologists hesitated to recommend palliative care due to its negative association with death. Public stigma refers to stereotyped thoughts based on general opinion [76]. Oncologists felt that this public stigma leads families to avoid considering palliative care. According to the study [55], both families and oncologists have unfavourable views of palliative care, with oncologists avoiding the term altogether as it can induce fear and symbolise a loss of hope. Label avoidance stigma occurs when someone avoids a particular management strategy because of the negative connotations that come with its name [77]. In the review [54] and the study [55], label avoidance stigma is also an issue as some oncologists avoid the term palliative care altogether, as it requires them to explain the concept to families.

Furthermore, the perception of public stigma and label avoidance stigma can give oncologists the power to exclude palliative care providers from the care process [78].

#### Task and efforts

The effort needed to complete a task impacts future exchange [62]. The contribution of a social actor towards the task is influenced by how fairly the effort-to-reward ratio is perceived [79]. Should this balance be unequal, the social actor's interest in the exchange relationship may decrease [80]. Consequently, the social actor's perception of the effort-to-reward ratio moderates social exchange behaviour [81].

In both review [54] and the study [55], oncologists found it challenging to make a referral for palliative care due to the many illness-related factors they had to consider. It includes aspects like progression of the disease, any complications, the stage of the illness, the presence of symptoms, the potential for a cure, the intent of treatment, the patient's prognosis, and their performance status. It was a significant effort to navigate this complex set of factors [54, 55].

#### Reward, cost, profit and value

Reinforcement is the act of selectively repeating a behaviour [56]. In social exchange relationships, reinforcement is a crucial concept, as it is closely tied to rewards, costs, profits, and value [82]. Socially significant actions will not be repeated unless reinforced [82]. Various rewards are discussed from a social exchange perspective [83]. These are not limited to physiological or materialistic benefits but can help fulfil higher self-actualisation needs [83].

The rewards from certain behaviours are connected to the immediate outcomes of those actions, which can impact future interactions [83]. Social actors first notice these rewards because they result from short-term associations [83]. In the review [54] and the study [55], oncologists appreciated behavioural rewards such as pain and symptom management, improved quality of life, better family coping, support for decision-making and advance care planning. The study [55] found that they appreciated the support provided by palliative care services for children at home during the terminal phase of the illness.

The benefits of having a continuous and extended relationship with others are known as relational rewards [83]. However, sometimes these rewards may not be immediately apparent due to the long-term nature of the relationship [83]. Some oncologists participating in the study [55] believed that a collaborative relationship could improve oncologists' productivity, reduce stress, improve treatment outcomes, and share responsibility for care. Saving the oncologists' time was the only relational reward noted in the review [54]. Self-actualisation rewards can bring about personal growth [83]. Self-actualisation rewards were only seen in the study findings [55]. A few oncologists reported that their association with palliative care had improved their symptom management and prognostication skills and their ability to empathise and show compassion.

When engaging in social exchange, the cost refers to the loss sustained in pursuing rewards [84]. It can be seen as either removing a positive reinforcer or applying a negative reinforcer [63]. If the cost is too high, it may cause the social actor to opt out of the exchange or choose an alternative [63]. The frequency of an activity is directly related to its cost, with more costly activities being undertaken less often. Profit, on the other hand, is the reward minus the cost. As long as the social actor stands to gain from the exchange, the process may continue [63]. The review [54] and the study [55] found that palliative care referrals can sometimes lead to confusion and mixed messages for the patient's family. It occurs when the palliative care team provides conflicting information about the patient's clinical condition, prognosis, and outcomes, leading to a disadvantage for the oncologists.

In addition to considering rewards, costs, and profits, social actors also consider the value of exchange [83]. This value is determined by the satisfaction the social actor derives from the activity and the positive emotions experienced during the exchange with another social actor [63]. Beyond the immediate and relational rewards, in the study [55], oncologists felt that early palliative care provides value to both patients and their families, as it helps build rapport with the palliative care team, ensures smooth transitions of care, and allows for symptom control and supportive care during cancer treatment. Additionally, it benefits oncologists by providing a reliable partner in the care process with whom they can trust, work with, and share responsibilities. The reciprocity norm dictates that the benefit received should be returned, and the provider should not be harmed [63]. Oncologists participating in the study [55] felt that palliative care providers should feel valued. According to the oncologists, palliative care providers should be valued and included as part of the oncology team to improve family acceptance of palliative care [55]. These align with earlier findings corresponding to power relationships and cost. By inviting palliative care providers to be part of the oncology team, oncologists can avoid sending mixed messages to patients and their families, which they identified as a cost of palliative care referral.

## Discussion

Social exchange theory [56] was initially only used to explain economic transactions in business relationships [85] and has faced criticism for having overlapping concepts and inadequate characterisation of domains and for portraying exchanges as purely economic [86, 87]. Despite this, the theory has since been applied to describe various human relationships outside economic contexts [88–91]. Social exchange theory has been previously used to understand physician referral behaviour in different clinical settings [25–29]. This is the first paper studying the utility of social exchange theory in a cancer setting by exploring oncologists' palliative care referral behaviour.

We aimed to determine if social exchange theory could explain oncologists' referral behaviour for palliative care [56]. Using a theoretical framework can assist in better comprehending and interpreting study or review results [92]. Evaluating a theory based on the data is essential, and empirical findings from a systematic review or study may either support, reject, or adjust the theory with an explanation [93]. We assessed the social exchange theory's relevance to cancer palliative care using a systematic review [54] and original research [55].

#### Step 7.2. Theory revision underpinned by data analysis

In this step the social exchange theory was evaluated in the light of empiric findings and modifications to theory was suggested. The first three study themes [55] and the initial four review themes [54] mentioned before fit well with social exchange theory [56]. However, when it came to discussing the strategies provided by oncologists to improve palliative care integration, we felt that social exchange theory was insufficient. As a result, we would like to suggest a critique and modification to the theory [56].

According to the social exchange theory, there are two levels of appraisal: the comparison level and the comparison level for alternatives [94, 95]. The comparison level evaluates the benefits and costs of social exchange, while the comparison level for alternatives involves considering other potential relationships that may be more rewarding [94, 95]. Social actors determine their level of satisfaction with a relationship based on the comparison level, and they remain committed to it as long as it is more profitable than other alternatives [63]. This decision depends on their knowledge of other relationships and the potential rewards and costs associated with them [94].

In the systematic review [54] and study findings [55], oncologists appraised the exchange relationship regarding benefit and cost. However, they did not discuss the possibility of choosing an alternative approach to referral or palliative care services for their patients. Instead, they provided strategies through which relationships between oncology and palliative care teams can be fostered and bettered, and the exchange process of referral may be improved. Sometimes, people may continue with a relationship due to a lack of better options or dependence [96, 97]. However, in both the systematic review [54] and

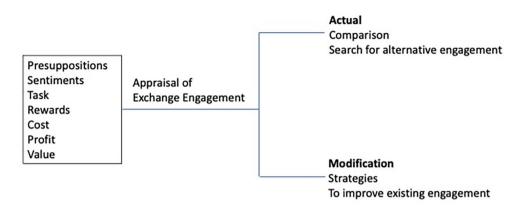


Fig. 1 Suggested modification to the social exchange theory

study findings [55], the oncologists valued the benefits of the relationship and provided strategies to integrate the teams. Therefore, it is suggested that adding feedback and solutions alongside a comparison level for alternatives represents a modification to the social exchange theory resulting from the systematic review data [54] and original research [55] (See Fig. 1).

#### Limitation and strengths

In the systematic review [54], The review analysed different types of studies, such as surveys, qualitative studies, and mixed methods studies, and found similar results. Furthermore, studies included in the review had participants from various oncology backgrounds and locations. The systematic review used to test social exchange theory had 21 primary studies from adult oncology and only two from paediatric oncology. Moreover, the data from the original study [55] used for theory testing had only paediatric oncologists as the participants. Therefore, the generalisability of findings to either adult or paediatric settings might be challenging, which could be a limitation. Furthermore, the systematic review [54] and the original research [55] focused on referral behaviour from the oncologists' perspective but did not consider the views of family members, palliative care providers, or other organizational factors.

#### Conclusion

In a cancer care setting, oncologists play a role in determining whether or not a patient is referred to palliative care. Social exchange theory has been used to explain physician referral behaviour in various healthcare settings other than cancer. Popper's hypothetico-deductive method demonstrated the utility of social exchange theory as an explanatory framework to describe oncologists' palliative care referral behaviour in a cancer setting. Most of the findings of the systematic review [54] and the original research [55] used to test the hypothesis correlated well with the tenets of social exchange theory. However, social exchange theory was limited by its lack of utility in interpreting study [55] and review [54] findings concerning strategies provided by the oncologists to enhance palliative care integration. Therefore, a theory revision is suggested by adding feedback and solutions alongside a comparison level for alternatives representing a modification to the social exchange theory resulting from the data used to test the hypothesis.

#### Acknowledgements

We thank the Tata Trusts and, Narotam Sekhsaria Foundation, for supporting this study. We also extend our thanks to faculty of Lancaster University and Kasturba Medical College, Manipal, for their invaluable assistance, both directly and indirectly, in our research.

#### Author contributions

NS, SH, and NP contributed towards formulating the research and review questions and developing review and research protocols. NS, SH, and NP contributed equally towards the systematic review. NS conducted all the research interviews and coded the transcripts. NS, SH, and NP contributed towards data analysis and theme generation. All authors contributed equally towards manuscript writing. The manuscript has been read and approved by all the authors, and all the authors meet ICJME requirements for authorship.

#### Funding

Naveen Salins expresses gratitude for the support given by the Tata Trusts and, Narotam Sekhsaria Foundation, in conducting this study. However, Nancy Preston and Sean Hughes received no funding for this research.

#### Data availability

The data produced or examined during this research has been incorporated into the published article.

#### Declarations

#### Ethics approval and consent to participate

The research conducted in this study was approved by the Indian (KMC/ KH IEC 292/2018) and the United Kingdom (FHMREC Lancaster University 17089/2018) ethics committees. Prior to taking part in the research, each participant gave written consent after being fully informed about the study. The authors affirm that all procedures were carried out in accordance with the applicable guidelines and regulations of the Declaration of Helsinki.

#### **Consent for publication**

Not applicable.

#### **Competing interests**

The authors declare no competing interests.

Received: 25 June 2023 / Accepted: 12 July 2024 Published online: 24 July 2024

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