

Research

Exploring district nurses' reluctance to refer palliative care patients for physiotherapy

Lesley Ann Nelson, Felicity Hasson, W George Kernohan

Globally, the provision of rehabilitation interventions in the palliative care model aims to ensure that patients' physical, psychological, social, and spiritual needs are fully met (World Health Organization, 2002). With advances in health care generally, patients are living longer yet often experience a range of multidimensional and complex health-care needs (Schleinich et al, 2008). Involving allied health professionals in the provision of palliative care may help in responding to some of these needs (Kumar and Jim, 2011). There is international acknowledgment that physiotherapists can make a significant contribution to the physical and functional dimensions of care for both malignant and non-malignant conditions (Laakso, 2006; Thoracic Society of Australia and New Zealand, 2008; Frymark et al, 2009; National Cancer Action Team (NCAT), 2009; 2010). Physiotherapists have also been explicitly included in multidisciplinary palliative care teams (Marcant and Rapin, 1993; Rashleigh, 1996; Hourigan and Josephson, 2004; Coyle, 2006).

Examples of physiotherapy interventions include respiratory care, management of dyspnoea, pain control, provision of exercise programmes, maximisation of mobility, and positioning to decrease pain and prevent pressure areas or contractures (Kumar and Jim, 2011). Physiotherapists also have a role in educating patients, carers, and other health professionals, disseminating information, and collaborating with primary and secondary care services (Belchamber and Everett, 2006).

However, pathways to referrals across Europe demonstrate considerable variation, ranging from self-referrals to intervention by a health professional such as a member of the primary care team or a medical specialist (World Confederation for Physical Therapy, 2011). Furthermore, in spite of the potential benefits, international evidence suggests that few palliative care patients receive care from physiotherapists (Chartered Society of Physiotherapists (CSP),

2004; Macmillan Cancer Support, 2010). This may be due to poor identification of patients' rehabilitation needs by front-line staff (NCAT, 2010), belief that rehabilitation is incongruent with the goals of palliative care (Cheville, 2001), and misconceptions around the role, contribution, and availability of existing rehabilitation services (CSP, 2004; Findlay et al, 2004; National Institute for Health and Clinical Excellence (NICE), 2004; Cott et al, 2007; Halkett et al, 2010; McCartney et al, 2011). Decisions regarding referrals to both palliative care services and rehabilitation services are complex and can be influenced by a range of clinical and non-clinical factors, including patient characteristics, referral processes, and provider preferences (Kennedy, 2005; Aitken, 2006; Walshe et al, 2008; 2009).

In the UK, access to rehabilitation services for patients based in the community is largely dependent on referral by members of the primary health-care team, including district nurses (DNs) (Beaver

Abstract

Aim: To explore district nurses' beliefs regarding referral of a patient receiving palliative care for physiotherapy. **Method:** Three focus groups, guided by the Theory of Planned Behaviour, were undertaken with a purposive sample of 16 district nurses. All were audio-recorded, transcribed, and subject to content analysis. **Results:** Nine beliefs were identified as influencing referral decisions, the majority of which were negative, such as the belief that physiotherapists lack palliative care skills and could foster false hope. Additional barriers to referral included a lack of contact and communication with physiotherapists, poor knowledge or experience of physiotherapy, unsuitable referral systems, and poor availability of services. **Conclusion:** These findings help to explain why so few patients receiving palliative care access rehabilitation services. To ensure that patients have appropriate access to palliative rehabilitation, there needs to be consideration of how the identified barriers can be overcome.

Key words: Physiotherapy ● District nurses ● Palliative care ● Theory of Planned Behaviour ● Focus groups ● Referrals

Lesley Ann Nelson is Specialist Palliative Care Physiotherapist, Community Specialist Palliative Care Team, Ards Community Hospital, Newtownards, Northern Ireland; **Felicity Hasson** is Senior Lecturer, Institute of Nursing Research and School of Nursing, University of Ulster, Newtownabbey, Shore Road, BT37 0QB, Northern Ireland; **W George Kernohan** is Professor of Health Research, Institute of Nursing Research and School of Nursing, University of Ulster, Northern Ireland

Correspondence to:
Felicity Hasson
f.hasson@ulster.ac.uk

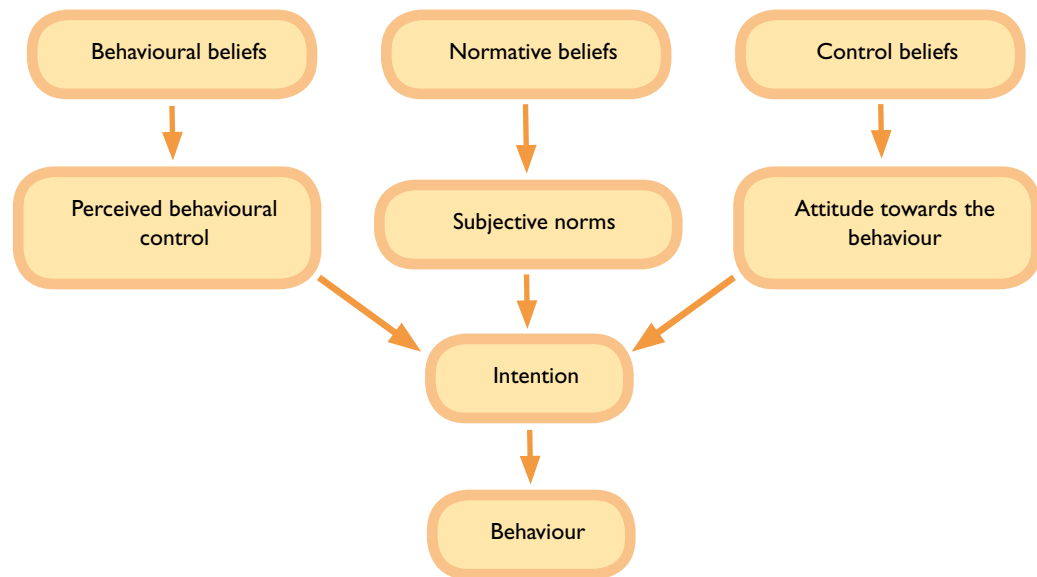


Figure 1. Ajzen’s (1991) Theory of Planned Behaviour showing how three types of beliefs influence behaviours. Adapted from Giles et al (2007).

et al, 2000; Dunne et al, 2005; Department of Health, 2008). Hence, referral to a physiotherapist is often dependent on the opinion of the DN and their understanding of the service (Bliss et al, 2000). However, little research has explored DNs’ decisions to refer a palliative care patient to rehabilitation services. Enhancing our understanding of such issues will clarify referral practices and consequently improve patient care.

The Theory of Planned Behaviour (TPB) (Ajzen, 1991) (Figure 1) has been used to explore and explain the relationship between attitudes and actions (Dwyer et al, 2005), including wide use in the study of a variety of health professional behaviours (Kam et al, 2010; Ward et al, 2010). It proposes that behaviour is influenced by three types of beliefs: behavioural beliefs (based on perceived advantages and disadvantages of performing a behaviour), normative beliefs (related to perceptions of social or peer pressure to perform a behaviour), and control beliefs (based on the perceived ease or difficulty of performing a behaviour) (Ajzen, 1991). The framework enables the researcher to identify beliefs that are specific to both the population of interest and the behaviour.

Aim

The aim of this study was to use the TPB to develop an understanding of DNs’ beliefs regarding referral of a patient receiving palliative care to physiotherapy. The findings should be useful in

addressing current shortcomings in patient care in this area and in guiding future research.

Method

A descriptive qualitative research design was adopted to identify and explore beliefs about referral. The study used focus groups to obtain insight into DNs’ rationales and motivations for their behaviours through exploration of their beliefs, understandings, opinions, and experiences. The focus group approach allows participants to stimulate each other to express their opinions and thereby reveal dimensions of deeper understanding than may be uncovered by other methods (Kitzinger, 2004).

Participants

A purposive sample of participants was drawn from a pre-existing group of DNs currently enrolled in two postgraduate courses at a university in Northern Ireland. The inclusion criteria required that participants have previous experience of working with patients receiving palliative care. With permission from the university, a recruitment pack was disseminated during term time to all of the DNs attending the courses. This contained a letter of invitation, a participant information sheet, and a consent form. Willing participants were asked to return completed consent forms with their contact details to the researcher within 2 weeks. From a total of 22 DNs, 16 agreed to participate.

Box 1. The focus group schedule of guiding questions, informed by three categories of belief

Behavioural beliefs

- What do you think are the advantages of referring a palliative care patient for physiotherapy?
- What do you think are the disadvantages?

Normative beliefs

- Would anyone in particular approve of you referring a palliative care patient for physiotherapy?
- Would anyone disapprove of you referring a patient for physiotherapy?
- Does anybody else come to mind when you are thinking about referring a patient receiving palliative care to physiotherapy?

Control beliefs

- What factors tend to prevent you from referring a patient receiving palliative care for physiotherapy?
- What factors facilitate you to refer a patient receiving palliative care for physiotherapy?
- Are there any other factors that affect your decision to refer a patient receiving palliative care for physiotherapy?

Box 2. Summary of the participant district nurses' beliefs

Behavioural beliefs (positive)

- Physiotherapy can be used to manage symptoms

Behavioural beliefs (negative)

- Physiotherapists do not have the necessary knowledge and skills required to provide good palliative care
- Introduction of physiotherapists would foster false hope among carers and patients
- Referral to physiotherapy would lead to too many professions being involved with the patient

Normative beliefs (either positive or negative)

- Opinions of nursing colleagues, hospice nurse specialists, GPs, patients and patients' families influence referral decisions

Control beliefs (negative)

- The district nurses had limited contact, knowledge, or experience of physiotherapy or physiotherapy interventions
- Referral systems are unsuitable for the client group
- Patients would be discharged from physiotherapy once the initial intervention was completed
- Physiotherapists are scarce or unavailable

Data collection

Three focus groups of four to six participants were conducted, with each lasting 30–45 minutes. Data was collected until saturation of themes occurred. Prior to commencement the participants completed an anonymous demographic questionnaire to elicit their gender,

employment status, qualifications, and palliative care experience. A focus group schedule of nine questions based on the TPB provided a framework for the discussion that was used to investigate the DNs' behavioural, normative, and control beliefs (Ajzen and Fishbein, 1980; Ajzen, 1991) (Box 1). Open-ended questions were used to allow the participants to express their salient beliefs; the interviews also remained flexible to enable responses to be clarified and probes used. Data was collected during 2010 by LN, who was not known to the students or involved in teaching within the institution.

Data analysis

With permission, the discussions were audio-recorded and later transcribed verbatim. These transcriptions were then checked for accuracy. Content analysis (informed by field notes) was conducted after each session following Newell and Burnard's (2006) six-stage framework whereby transcripts are read several times and then categories are identified and refined. The coding of response categories was guided and labelled by the TPB, using behavioural, normative, and control beliefs. To ensure reliability of the coding process and analysis, two researchers independently analysed the data.

Ethical considerations

No ethical concerns or potential harms were identified. Ethical approval was obtained from the local university ethics committee. Approval for the study was also obtained from the Directors of Nursing and the Head of School. Written consent was gained prior to the commencement of data collection. The participants were informed both verbally and in writing that they were under no obligation to participate and were advised that they could withdraw from the study at any stage without detriment. Participant confidentiality was assured through the application of 'ground rules' and the adoption of good practice.

Results

The 16 participants were all female and they had been working as nurses for a mean of 18 years; most had been employed as a DN for over 7 years. Their employment settings were a mixture of urban (38%), rural (44%), and a combination of the two (19%). The findings from the study are presented using the three TPB belief categories (see Box 2 for a summary).

Behavioural beliefs

Four behavioural beliefs were identified, one positive and three negative. The positive belief

was that referring a palliative care patient to physiotherapy can be helpful in the management of symptoms, such as respiratory secretions, poor mobility, and lymphoedema. Most of the participants were aware of the role of the physiotherapist in the management of lymphoedema, and a few had experienced patients benefitting from massage, bandaging, and the provision of compression sleeves and stockings.

The other three behavioural beliefs were negative: that physiotherapists do not have the necessary knowledge and skills required to provide good palliative care, that their introduction would foster false hope among carers and patients, and finally that referral to physiotherapy would lead to too many professions being involved with the patient. There was a consensus that the provision of good palliative care requires a holistic approach to the assessment and management of the patient, the building of a relationship with both the patient and their family, and the acquisition of some additional skills and training. Physiotherapists were perceived as being task-orientated and as lacking palliative care training, and as a result they were deemed to be unable to respond to the psychological, social, and spiritual needs of the patient.

'... with palliative patients, you have to adopt a certain ethos. Sometimes physiotherapists, they just don't have the same sympathy for the patients and they don't understand the palliative aspect of their care.' Focus group 2, participant 8 (F2 P8)

The participants expected physiotherapy interventions to be infrequent and brief, thus preventing the building of a relationship with the patient and family. They also thought that such interventions would be withdrawn when patients' health deteriorated, with the potential to cause upset and distress.

'You just don't go into someone's house who has palliative care needs and expect to build up a rapport or relationships in one visit ... We're in there day and daily; physiotherapy is not that kind of service.' F2 P8

'You can't put in an input and then take it away because someone is entering the end stage disease, that's like pulling the carpet from under them I feel.' F3 P14

The belief that physiotherapy could foster false hope was based on the strong association between

physiotherapy and the traditional concepts of rehabilitation that are around recovery.

'I think sometimes maybe a physiotherapist coming into the house might foster false hope, again going back to the rehab issue.' F2 P11

The need to minimise the number of health professionals involved with a patient receiving palliative care led to non-referral. The need to protect carers, enhance coordination of care, and decrease confusion about professional roles and boundaries resulted in participants being reluctant to add to the number of people involved.

'One big disadvantage if you're talking about end-stage care, sometimes there can be just too many people involved.' F3 P14

Normative beliefs

One normative belief was recorded. When asked whether there were people whose opinions were likely to influence the decision to make a referral, reference was made to nursing colleagues, hospice nurse specialists, GPs, and patients and their families. Although professional colleagues were identified, the opinions of patients and their families appeared to have a much greater impact on the DNs' decisions, and this impact could be either negative or positive.

'... I think patients as well, can't sometimes see, if you suggested getting the physiotherapist out to see them and they're dying of cancer, maybe 6 months to live, they'd say "What do I need a physiotherapist for?"' F1 P5

Control beliefs

No control beliefs facilitating referrals were identified; four barriers to referral were raised. The DNs had limited contact with, knowledge of, or experience of physiotherapists or their interventions. As a result, they said that they often did not consider a referral to physiotherapy as it was not part of their usual practice. They had no informal opportunities to discuss cases with a physiotherapist to check whether a referral could be appropriate. If they did consider making a referral they were unsure how to access such services in either the community or the hospital sector:

'You don't really see them out in the community like you would see the rest of the team ...' F2 P6

The participants felt that this lack of contact prevented them from building a better working

'... in spite of the potential benefits, international evidence suggests that few palliative care patients receive care from physiotherapists ...'

‘The district nurses had limited contact with, knowledge of, or experience of physiotherapists ... they often did not consider a referral to physiotherapy as it was not part of their usual practice.’

relationship or improving their understanding of the role of physiotherapy, its benefits, and when and how to refer. Physiotherapists were described by several participants as being last on the list of professionals that they would consider referring a patient receiving palliative care to.

‘With community physiotherapy you are not aware of who they all are, what their practices are, who covers what team and what their remit is, so you don’t refer, because you nearly think, what is the point ... it’s probably out of their remit.’ F1 P3

A further barrier was the belief that systems for referral to physiotherapy are unsuitable for patients receiving palliative care, in particular because of the absence of any mechanism to informally discuss potential referrals before submitting them. The opportunity to discuss referrals before formal application was considered vital to ensure appropriateness, to fully describe the patient’s needs, and to ensure that the service would be provided in a timely manner given patients’ constantly changing circumstances and problems. Many of the participants believed that if it was not possible to make this kind of contact then it was best not to proceed with the referral. There was also a general belief that the response times of the current referral system were slow, resulting in a time lag of several weeks before a physiotherapist would visit.

‘I know whenever you make a referral to physiotherapy for stroke rehab or something like that, you could be waiting 6, 8 or 10 weeks maybe to get a physiotherapist out, so you’re thinking, “End of life, is there any point in putting in a referral, they could be dead and buried by the time the physiotherapist knocks the door”, so that would be another thing that would impede you.’ F1 P5

If a referral was made the participants believed that patients would be discharged from physiotherapy once the initial intervention was completed, requiring them to make subsequent repeat referrals to the service if the patient’s condition changed, increasing their workload.

‘Physiotherapists will only keep them on their caseload for a while and then discharge them. So you [would] have to keep re-referring them all the time.’ F3 P13

A final barrier to referral was a general perception that physiotherapists in the community were either scarce or unavailable. Physiotherapists

with specialist palliative care skills were perceived to be a particularly scarce resource.

‘...even finding physiotherapists that actually specialise in palliative care, you know have an interest ... I think they’re a bit few on the ground.’ F2 P8

Enhancing referral rates

The participants made a number of spontaneous suggestions to improve referral practice including having access to more information about physiotherapy services, a named physiotherapy contact in their locality with whom referrals could be discussed, improved referral processes, and more joint working between DNs and community physiotherapists.

Discussion

The purpose of this study was to improve understanding of DNs’ attitudes and beliefs regarding referral to physiotherapy services of patients at the palliative care stage. Although there is an expectation that DNs are involved in planning care and supporting their patients, the study highlighted that the process of engaging with physiotherapy is not straightforward. Using the TPB it was demonstrated that a range of beliefs influenced the referral decision-making process, and that there were many more barriers than facilitators. For example, there was poor knowledge of and many misconceptions about the physiotherapists’ role, skills, and services. Such findings reflect previous research that has explored why rehabilitation services are under-utilised (NICE, 2004; Findlay et al, 2004; Cott et al, 2007; Halkett et al, 2010).

The findings are consistent with previous research which suggests that there is inconsistent understanding of the contribution that rehabilitation interventions can make in palliative care (NCAT, 2010; Halkett et al, 2010; McCartney et al, 2011). DNs may have a limited view of the role of physiotherapy, linking it with recovery and believing that it is not integral to palliative patient care. Earlier research also found a lack of understanding of what physiotherapy can offer (NICE, 2004; Findlay et al, 2004; Cott et al, 2007). Unfortunately this can contribute to the poor identification of and response to the rehabilitative needs of palliative care patients (Cheville, 2001; Schleinich et al, 2008; Macmillan Cancer Support, 2010).

Another barrier to referral identified here that was reflective of other studies (Aitken, 2006; Walshe et al, 2008; 2009) was the perception that physiotherapists lack palliative care knowledge

and skills, instead adopting a task-driven and time-limited care intervention. It is possible that such misgivings may be partially justified, as previous research suggests that physiotherapists do not have ready access to palliative care training (CSP, 2004; Findlay et al, 2004).


The behavioural belief that referral to physiotherapy may result in too many professionals being involved with the patient corroborates previous research highlighting a requirement for DNs to balance the needs of patients with managed influx of professionals into the home (Kennedy, 2005; Aitken, 2006). Given the patients' poor prognosis, their private time with family needs to be protected. In addition, the more professionals that are involved, the greater the potential for role confusion (Beaver et al, 2000) and the greater the need for the DN to coordinate the various professionals and facilitate communication between them (Dunne et al, 2005).

Limitations of the study

These findings should be interpreted with caution as the study is based on a limited purposive sample. No claims are made that the sample is representative of all DNs or all nursing students attending courses in the UK. Although the results do provide insight into some of the factors that may influence referral rates, a different approach would be needed to examine generalisability to the wider DN population in the UK. Second, although focus groups enable spontaneity of expression, dominant personalities can inhibit the expression of alternative viewpoints. This was minimised by using small group sizes. Finally, although the TPB provided a useful framework to explore DNs' beliefs regarding referral to physiotherapy, it is recognised that individuals do not always behave as predicted by this first-order model. Other factors such as personality and emotions also influence behaviour. Despite these limitations this study provides a valuable insight into referral practice. The main findings are reflective of the national and international literature.

Conclusion

A range of factors were found to militate against referral to physiotherapy for palliative care patients. The majority of the behavioural normative and control beliefs identified were negative, tending to act as barriers against referral to rehabilitation services. The TPB helps to explain the DNs' salient beliefs and the barriers to referral to physiotherapy. As rehabilitation in palliative care is advocated and the evidence base for its provision

is growing, inappropriate beliefs about referrals need to be explored and challenged. Nurse educators, policy makers, and managers need to address negative attitudes to ensure that palliative care patients are being offered the care that they require. Physiotherapists need to be actively involved to encourage and educate DNs on their role and the benefits of the interventions they can offer to patients and carers. Further research is warranted to explore referral practices and find opportunities to promote such behaviour between primary care and allied health professionals on a larger scale, perhaps using a variety of approaches to improve access to rehabilitation services for palliative care patients. 

‘Physiotherapists need to be actively involved to encourage and educate district nurses on their role and the benefits of the interventions they can offer to patients and carers.’

Acknowledgments

The authors greatly appreciate the contribution of the district nurses who took part in this study and the educational staff who facilitated access.

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