

2019-03-20

Promoting the use of outcome measures across disciplines through action research with practitioners in a palliative care setting.

Reynolds, Sarah

<http://hdl.handle.net/10026.1/12712>

10.12968/ijtr.2017.0104

International Journal of Therapy and Rehabilitation

Mark Allen Healthcare

All content in PEARL is protected by copyright law. Author manuscripts are made available in accordance with publisher policies. Please cite only the published version using the details provided on the item record or document. In the absence of an open licence (e.g. Creative Commons), permissions for further reuse of content should be sought from the publisher or author.

International Journal of Therapy and Rehabilitation

Promoting the use of outcome measures across disciplines through action research with practitioners in a palliative care setting.

--Manuscript Draft--

Manuscript Number:	ijtr.2017.0104R1
Article Type:	Original research
Keywords:	rehabilitation; outcome measures; palliative care.
Corresponding Author:	Sarah Reynolds University of Plymouth Plymouth, Devon UNITED KINGDOM
First Author:	Sarah Reynolds
Order of Authors:	Sarah Reynolds Katrina Bannigan, Dr
Abstract:	<p>Abstract:</p> <p>Introduction Allied Health Professionals aspire to being evidence-based practitioners but disparity exists between best practice and clinical practice. One example is outcome measurement; despite being committed to using outcome measures, allied health professionals struggle to use them. This study aimed to explore the process of introducing outcome measures into a practice setting.</p> <p>Method A qualitative action research study was undertaken with allied health professionals working in a hospice setting. The data, collected in three cycles of action, was analysed thematically.</p> <p>Findings Three themes emerged: the gap between knowledge and practice, the challenges of measuring outcomes in palliative care, and facilitators to using outcome measures in palliative care. Action research provided a structure to involve therapists in introducing outcome measures within a practice setting.</p> <p>Conclusion This study provides insight into how a clinical speciality's discrete characteristics influence the process of selecting outcome measures. In a hospice setting, where people have life-shortening conditions, the challenges for using outcome measures are different to other settings. Action research offers a deep learning opportunity and process, through education, discussion, and critique, to support therapists to select and adopt the outcome measures to use in practice.</p>

Title page

Promoting the use of outcome measures across disciplines: ~~Action research~~ through action research with practitioners in a palliative care setting .

Category: Research

Authors: Sarah Reynolds and Dr Katrina Bannigan

Sarah Reynolds MSc APP, DipCOT, Lecturer in Occupational Therapy,

Faculty of Health and Human Sciences, Plymouth University, PAHC, Derriford Road, Plymouth, Devon, PL6 8BH. Email: sarah.reynolds@plymouth.ac.uk

and Occupational Therapist, Torbay and South Devon NHS Foundation Trust,

Email: s.reynolds2@nhs.net

Dr Katrina Bannigan, Associate Professor (Reader) of Occupational Therapy, Plymouth University and lead for 'Participation in Everyday Life' research group

Faculty of Health and Human Sciences, PAHC, Derriford Road, Plymouth, Devon, PL6 8BH, United Kingdom. Email: katrina.bannigan@plymouth.ac.uk

Author responsible for correspondence:

Sarah Reynolds, Faculty of Health and Human Sciences, Plymouth University, PAHC, Derriford Road, Plymouth, Devon, PL6 8BH. Email: sarah.reynolds@plymouth.ac.uk

Personal phone number 07967 655053

[Type text]

Introduction

Outcome measurement, which involves the use of standardised assessments to measure change in patients functioning, performance or participation over time (Duncan and Murray, 2012), is a core component of evidence-based practice.

Evidence-based practice is core to practice in the allied health professions. Yet outcome measures, although required by commissioners of services and

professional bodies, have not been routinely used by allied health professionals

(College of Occupational Therapists [COT] 2013, Duncan and Murray, 2012), or,

indeed, by palliative care services (Bausewein et al 2016). The first author worked in

a hospice in England where neither occupational therapy nor physiotherapy services had a systematic way to identify how their interventions affected their service users.

This apparent discrepancy between mandate and practice led to an action research study to explore the process of introducing outcome measures into a practice setting.

Henceforth, occupational therapists and physiotherapists will be referred to as Allied Health Professionals (AHPs).

Literature review

Literature concerning outcome measurement was reviewed, and outcome measures have been criticised, internationally, for their lack of utility generally; for example, due to lengthy administration time (Krasny-Pachini et al 2013, Duncan and Murray, 2012). Time to administer is an important issue for AHPs who work with people, such as those receiving palliative care, who experience symptoms such as pain and

[Type text]

fatigue. As well as symptoms, patients' culture, literacy and language, and the quality of organisational support has-were also been found to influence outcome measurement uptake (Duncan and Murray 2012).

Use of outcome measures in palliative care

Working with people who have a life-shortening condition provides an additional challenge when selecting valid measures. Some recommendations from the UK exist for occupational therapists working with people with motor neurone disease (COT 2015). In palliative care settings, specifically, it is suggested the reasons health care professionals do not use outcome measures are: a lack of staff training, time constraints, patient burden and difficulty choosing tools (Bausewein et al 2015), as well as the inadequacy of outcome measures to measure meaningful change (Etkind et al 2015). There are factors that have been found to positively influence use of outcome measures in palliative care. Unsurprisingly, both administration flexibility, to allow for fluctuating end-of-life ability, and speedily administered measures, enabled clinical utility (Evans et al 2013). A systematic review of the use of patient reported outcome measures concluded that identifying specific barriers to using outcome measure supported successful implementation (Antunes et al 2014).

Few studies were found that discussed use of measures by AHPs working in palliative care. The Palliative Care Outcome Scale (POS), was identified as having potential by Pearson et al (2007). More recently, Witt et al (2015) recommended multi-disciplinary teams use a suite of measures comprising the Integrated Palliative

[Type text]

Care Outcome Scale (IPOS) (developed from POS), the Karnofsky Performance Status, and the Barthel index. An earlier version of IPOS, the Palliative Care Outcome Scale (POS), had previously been identified as having potential (Pearson et al 2007). However, as IPOS does not include any measurement of participation in everyday life. Participation, defined as 'involvement in a life situation' (World Health Organisation [WHO], 2002, p.10), is embedded in the International Classification of Functioning, Disability and Health (ICF) health classification model (WHO, 2014). Participation is a key aim of palliative rehabilitation (Eva and Morgan, 2018, Brant et al, 2016). Therefore, it could be argued that AHPs require an additional outcome measure to address this. focuses on symptoms rather than participation in meaningful occupations, it could be argued it has limited relevance for AHPs. Some Outcome measures such as the Therapy Outcome Measures (TOMs) (Enderby and John 2015), and AusTOMs (Unsworth and Duncombe 2014), do seek to measure participation: - their respective authors have suggested TOMs and AusTOMs should be used in palliative care. AusTOMs has also been cited in the occupational therapy guidelines discussed above (Smith and Edwards 2011, COT 2015).

The use of goal setting outcome measures, have also been promoted, for example, Goal Attainment Scaling (GAS) (Wosahlo and Maddocks 2015); and the Canadian Occupational Performance Model (COPM) (Carey et al 2013). cited in COT 2015a, p.5). The use of GAS in palliative care has been criticised: Poulsen et al. (2014) suggested that people with life-limiting conditions can set unrealistic goals and Krasny-Pachini et al.(2013) identified that GAS can be time-consuming to administer. A small study, conducted in a hospice, concluded that occupational therapists frequently discussed goals with patients but rarely documented them (Wosahlo and

[Type text]

Maddocks, 2015). Therefore, the literature presents a mixed picture concerning goal achievement as an outcome measure.

As the use of outcome measures is not straightforward for AHPs, the aim of this study was to explore the process of introducing outcome measures into a practice setting. The objectives were to discover why the AHPs were not using outcome measures and to address those issues to introduce an outcome measure with clinical utility.

Method

The AHPs working in the same hospice as the first author, wanted to start using outcome measures that measured the effect of their therapy. As the aim was to explore the process of introducing outcome measures into a practice setting, which involved a change to practice, participatory action research (Kemmis and McTaggart, 2005) was chosen. Participatory action research is the only research methodology that focuses on change and researching change at the same time, whilst seeking the opinions of the people the change affects. involves 'a cycle of events that is intended to help the practitioner evaluate and modify practice' (Hicks 2009, p.9). Furthermore, the process allows for cycles of action to be identified that Another reason for selecting action research was because it can address problems from different viewpoints. For example, it enables professional collaboration to address practice issues, and also allows the process to be researcher-led, so the same issues can be addressed from an organisational stance (Hart and Bond, 1995). This action research study was a combination of both approaches.

[Type text]

Data ~~was~~ **were** collected using cycles of action **that involved** ~~involving~~ a series of meetings (see figure 1) **which were** ~~that~~ focused on discovering why outcome measures were not being used and addressing those issues. **Such cycles of action involve planning, acting on and observing the process of change, then planning again, whilst evolving understanding and changes to practice (Kemmis and McTaggart, 2005).** **All occupational therapy and physiotherapy staff employed by the organisation were invited to attend the meetings.** As the first author was a clinician within the team, with additional management duties, ~~there was~~ the potential for the abuse of power and a risk of bias **was recognised**. To mitigate this, potential participants were assured that involvement was voluntary, and that all opinions would be respected. Furthermore, **the researcher appointed** an independent facilitator ~~was appointed~~ to lead the research group meetings. The facilitator **who** also acted as a 'critical friend' by challenging issues as they arose (Rudestam and Newton 2015). A research diary was kept alongside the cycles of action to aid reflexivity.

Data ~~was~~ **were** collected in three cycles of action—three meetings of the research group—which evolved during the study (see figure 1). The meetings were organised around the therapists' working patterns and managed by the lead author. Progress charts and action plans were created during each meeting (Stringer 2014) and they were audio recorded and transcribed verbatim **by the primary researcher** to ensure trustworthiness. Each group member received an email summary following each meeting, so they could check the data for accuracy. The summary of each cycle informed the next action research cycle. The research group meetings transcripts were analysed inductively **by the primary researcher** using a coding approach to

[Type text]

unearth emerging themes (Miles et al 2014). Ethical approval was obtained from the University of Plymouth Faculty of Health and Human Sciences **Ethics Committee** (study HS14/15-159) and approved by the hospice Quality and Patient Safety Committee.

<<Insert figure 1 here>>

The action research cycles

Three cycles of action took place over three months and there were four weeks between each one. ~~Attendance at the three meetings varied.~~ **Whilst all the occupational therapy and physiotherapy staff volunteered to participate, attendance at each meeting varied due to the need to prioritise clinical duties. Both occupational therapy and physiotherapy staff were represented at each meeting. The facilitator attended each meeting.** The initial meeting was attended by seven AHPs ~~as well as a facilitator~~ (three occupational therapists, two physiotherapists, one occupational therapy technical instructor and a student). Six participants attended the next two meetings. ~~Whilst attendance varied, both occupational therapy and physiotherapy staff were represented at each meeting.~~ How the three cycles of action evolved is summarised in figure 1, **and are detailed in table 1.**

<<Insert table 1 here>>

Action research cycle 1: Initial research meeting

[Type text]

At the initial meeting the aim was to understand why the AHPs were not often using outcome measures. The AHPs discussed their understanding of outcome measures and their perspectives on outcome measurement within their setting, to discover why they were not using outcome measures. As they were a small interdisciplinary team, they considered the requirements for an outcome measure that could be used by both occupational therapists and physiotherapists. The AHPs discussed potential barriers, and facilitators, to using outcome measures at the hospice. The resulting ideas were organised into categories by the research group, which formed the basis for a wish list of outcome measure requirements that the AHPs wanted met.

The AHPs shared their knowledge of outcome measures they used, and others that they thought may have value at the hospice, i.e.

- Patient reported outcome measures (PROMs) including patient-reported breathlessness, pain and fatigue scales;
- Therapist completed evaluation tools;
- The Palliative care Outcome Scale (POS) (Cicely Saunders Institute, 2012);
- TOMs.

The discussion highlighted that the AHPs were not fully cognisant with the POS and TOMs. Therefore, in the spirit of action research, it was agreed that information about POS and TOMs would be sought and disseminated at the next meeting.

Finally the group concluded that they wanted to explore the utility of numerical rating scales or visual analogue scales (such as breathlessness, fatigue or pain scales), POS, GAS, or TOMs within their setting.

[Type text]

<<Insert Table 1 here>>

Action research cycle 2: Considering the need of the hospice

The second meeting began with the group member who had suggested the Palliative care Outcome Scale, clarifying they had actually used POS-symptoms (POS-s); a measure under the POS umbrella that enables self-report of the severity of symptoms and impact on quality of life (Cicely Saunders Institute 2012). The first author shared her knowledge of TOMs, having attended a TOMs Community Therapists Network workshop. The group then discussed their perceptions of how the outcome measures they had selected (Numerical rating scales/visual analogue scales, POS-s, GAS and TOMs) would meet their clinical requirements, by marking each tool against the categories in their wish list (Table 1) with a yes, no, or unsure (Table 1). POS-s and TOMs rated the highest against their wish list. To deepen their understanding of each measure's clinical utility the group decided that TOMs and POS-s would be applied to two anonymised patient scenarios in the final action research meeting.

<<Insert Table 4 2 here>>

Action research cycle 3: Agreeing a measure

Two patient scenarios were introduced by two separate AHPs and the group individually assessed TOMs' and POS-s' clinical utility using a checklist (see Box 1).

<<Insert BOX 1 here>>

[Type text]

The checklist was a condensed version of their wish-list and each item was assessed using a five point Likert scale. The group identified that both outcome measures had different qualities. In general, they rated TOMs highly for participation, relevance to palliative care, ease of learning and interpretation and, because it is therapist rated, it was deemed suitable by the majority for use with cognitively impaired patients. However, one group member perceived TOMs would not demonstrate clear outcomes. The group rated POS-s highly for symptom measurement, which is what it is designed for. They agreed that although POS-s measured the impact that symptoms had on wellbeing, it did not measure the impact that symptoms had on participation. The group had already established that they needed to measure patients' participation in their meaningful occupations, as well as symptom changes to assess the impact of the rehabilitation they provide. Action cycle three concluded with an agreement to evaluate TOMs in practice.

The group decided that the first author would recommend to the hospice quality, innovation, productivity and prevention group (QUIPPS) that the AHPs would use TOMs initially with twenty patients, and then reconvene to review its use. This recommendation was accepted by QUIPPS after the action research project was completed.

<<Insert BOX 1 here>>

Findings and discussion

Three overarching themes emerged from the data analysis. The themes are: titled 'the gap between knowledge and practice'; 'the challenges of measuring outcome in palliative care'; and 'facilitators to introducing an outcome measure in a palliative care setting'. Each is presented and illustrated with verbatim quotations from the

[Type text]

group members; the code after each quotation identifies which participant said it and in which action cycle, i.e. (P3AC1) means participant 3 **said it** in action cycle 1. An overview of the individual participants is not provided to protect participant anonymity, because in a small team in a specialist practice area, it may be possible to determine which participants had said what. The significance to the setting, and the wider field of occupational therapy and physiotherapy, are considered in the discussion of the findings.

The gap between knowledge and practice

The AHPs knew they should capture information about their patient's participation in their everyday lives, but they were not actually doing this; a clear gap between their knowledge and their practice. The AHPs were measuring patients' symptoms, but not their participation in everyday life. Symptom measurement is regarded as appropriate when offering palliative symptom management (Smith and Edwards 2011). However, it has long been recognised that AHPs should focus on outcomes of function and participation (Smith and Edwards 2011; HCPC 2013a; HCPC 2013b), and the group understood this. One participant posited that symptoms should be measured precisely because of their impact on participation:

'but those symptoms can be the blocks to participation(.) If you're feeling sick and in pain all the time then you're not going to ... participate in your normal [activities](.) ' (P5AC3)

[Type text]

Yet, the group recognised that symptom measurement alone did not fully evaluate rehabilitation goals:

‘are we just looking to sort out symptoms (?) Or are we looking to enable participation for people (?)’ (P3AC3)

The group were not able to agree a definition of ‘participation’:

‘what “participation” as a thing or just ‘participation’ in general (?)’ (P7AC1)

‘Say the activities (.) I dunno is that a bit vague (.)’ (P5AC1)

The group struggled to articulate the meaning of participation **in practice although they knew it was a concept.** Although it is a generally held opinion that AHPs should be able to ~~do this this~~ **explain the meaning** (Backman 2005), others **such as Larsson-Lund and Nyman (2017)** and Hemmingsson and Jonsson (2005) have **acknowledged how difficult it is to define or quantify** ~~the challenge in quantifying participatory activities~~ **what is meant by participation.** **Yet,** the group recognised that outcome measures **that measured participation** ~~that~~ had potential to demonstrate the impact of their rehabilitation more effectively than completed case notes alone. It was acknowledged that the nature of case note narratives made data extraction difficult:

[Type text]

'...erm you could find the evidence there but it might mean kina trawling through text...' (P5AC1)

The group also knew that stakeholders, The group also identified a range of stakeholders such as commissioners and the local community, who might want evidence of rehabilitation outcomes, but they did not have a way of providing this evidence. This was another example of the knowledge / practice gap. This resulted in discussion that 'outcomes' may mean different things to different stakeholders, reflecting an issue that has long been recognised in the literature (Austin and Clark 1993). Service commissioners were one example offered:

'to prove we're getting value for money to (.) like (.) commissioners (.)' (P2AC1)

It has been suggested that palliative care services should communicate clinical improvements to commissioners (Bausewein et al 2015) and, in particular, that hospices should show benefits of rehabilitation (Tiberini and Richardson 2015) which the group were cognisant of:

'it's at different levels isn't it (.) so you've got like your err government level (.) um with CQC clinical governance and that (.) then you've got your commissioners which is more like local (.) and then (.) you've got more ground within referrers' (P6AC1)

[Type text]

Furthermore, it seems sensible that AHPs communicate the impact of their services to service commissioners through senior organisational managers. One AHP participating in the group identified that outcomes data had indeed been provided to managers to support a new intervention:

'In the acupuncture pilot if I'd gone back and said oh this is some of the comments from patients and patient quotes rather than like hard evidence on the POS [sic] scores I don't (.) I wouldn't have got it (.)' (P8AC2)

Such understanding of the significance of convincing budget holders that a service is worth commissioning came because the action research participant had experienced success when introducing a specific treatment modality. This P8 contribution demonstrated how action research extended other participants' knowledge.

The group also strongly knew that they should be ~~were~~ accountable to their local fundraising community, due to the hospice's charitable status:

'... we've got like the general public (.) if they didn't think we were doing a good job (.) they're not going to contribute (.) if they don't contribute we don't continue (.)' (P2AC1)

[Type text]

This **The publication of rehabilitation outcomes** appears to be a new **consideration** perspective; ~~no literature was identified of rehabilitation outcomes for hospices,~~ although Help the Hospices (2014) urged hospices to discuss quality with trustees, staff and users. The concern regarding the hospice financial sustainability echoes recent findings regarding fragility of hospice funding (Hospice UK and Together for Short Lives 2015). ~~One AHP participating in the group identified that outcomes data had indeed been provided to managers to support a new intervention:~~

~~'In the acupuncture pilot if I'd gone back and said oh this is some of the comments from patients and patient quotes rather than like hard evidence on the POS [sic] scores I don't (.) I wouldn't have got it (.)' (P8AC2)~~

Furthermore, the participants were aware that their professional organisations advocated outcome measurement (CSP 2012; COT 2013), and that their standards of proficiency also required it (HCPC 2013a; HCPC 2013b). Nevertheless, this study found **there was a** clear discrepancy between professional mandate and practice, **as has been** observed in the literature (**Bausewein et al, 2015; Duncan and Murray, 2012**). ~~was reflected in this practice setting.~~

The AHPs in this action research **also considered the key issue of evidence-based practice**. **They** discussed **the need to**, ~~why they needed to~~ promote the use of outcome measures to demonstrate the impact of rehabilitation.

[Type text]

'That's what we want at the end of the day (.) something that can help us know what has worked or what we need to change or work on next (.)' (P5AC1)

'it's nice to use as feedback (.) "look this is where you were and this is where you are now" (.)' (P8AC2)

~~It is known that~~ Clinicians may be more likely to accept outcome measures if pertinent to patients (Bausewein et al 2015). It is suggested, therefore, that those promoting the use of outcome measures ~~to clinicians~~ should emphasise the patient benefit ~~this was also~~ **as** recommended by Antunes et al (2015). Indeed, a personalised approach to addressing stakeholder requirements may also be advisable. For example, whilst the message to trustees or commissioners may concentrate on patient benefit, AHPs ~~might additionally be reminded of professional codes of conduct expectations~~ **also need to consider their codes of conduct.**

Knowledge of specific outcome measures

Clinical experience affected knowledge of particular outcome measures: participants called upon their past and present experience. ~~As~~ **Since** qualified staff, technical instructors, and a student participated in the study, it ~~could be~~ **was** anticipated that knowledge might vary and this was the case. In the hospice setting, the AHPs were primarily using two types of outcome measures: uni-dimensional PROMs, such as visual analogue scores, and POS-s. However, they were not using either consistently. The participants identified a problem with time constraints:

[Type text]

'sometimes it's just time you know (...) you're so busy doing the job that you know (.) the outcome measures won't don't come into it and that's why it's good to have this really (.) to focus on what outcome measures to use (.) it might you know there might be something really good out there that we've overlooked just because of time constraints (.)' (P8AC2)

~~This problem for time-pressured clinicians was identified by Bausewein et al (2015)~~ also **found that clinicians**, who identified the difficulty of finding, and selecting suitable measures **when time-pressured**.

The challenges of measuring outcome in palliative care

The participants revealed that the palliative care setting presented particular challenges to using outcome measures. Deterioration in patients' health was one example:

'[...] and there was one patient where one of them [the score] had gone down but he (.) he had the insight himself to say "well I feel less well in myself (.) I know things are changing so I don't (.) you know (.) this course has been really useful but it (.) that's not why it's gone down but it's because like I feel less well" (.)' (P5AC2)

[Type text]

Deterioration affects a person's occupational engagement, and therefore their goals.

When discussing goal achievement P3 (in AC1) stated:

'if we measure something in that sort of way it might look as if we're failing but actually it's just the disease overtaking (.)'

The difficulty in capturing the effectiveness of interventions in palliative care is acknowledged in the literature (COT 2015). Patients and families need support from diagnosis through to death. Indeed, the group members valued their role in supportive care opposed to traditional rehabilitation:

'One big thing is having people come to terms actually...sometimes this is where our role here can actually be the opposite to...anything we've done...in any other setting ... you're actually spending a lot of time helping someone come to terms with the fact they're not going to do that again (.)' (P5AC1)

Equally, patients may receive concurrent treatments to address problems: this was another challenge to measuring outcomes. It would undoubtedly be unethical to restrict treatments to test the efficacy of one specific intervention. A participant explained this difficulty:

[Type text]

'the change you see isn't necessarily attributable to the therapy or even if you feel it is (.) proving that (.) and often that is really hard as often there are so many other things going on [...] they've been put on an anti-depressant or all those other things going on (.)' (P5AC2)

It is acknowledged that more palliative care research is required to ascertain evidence-based interventions (Bausewein et al 2015). However, high attrition rates due to ill health or death is a barrier to research (Evans et al 2013). PROMs have been suggested as a means to understand patient needs (Bausewein et al 2015) but the group members were concerned that PROMS would overburden patients.

'you don't want to be a constant reminder "are you in pain" if they have total pain and they just think they've more again and you just try to divert away for a little bit rather than start asking questions again (.)' (P7AC3)

These findings echo other studies; tool burden was found to be a barrier for patients approaching end-of-life (e.g. Pearson et al 2007). Additionally, the participants perceived it was important to avoid assessment duplication, both by individual therapists, and the multi-disciplinary team. ~~In this setting, the community team therapists held responsibility for symptom assessment if they were the lone professional seeing that patient.~~ **In contrast, when no other clinician was involved in the patient's care, the AHP's needed to assess symptoms: This was sometimes the case for patients receiving community team support:**

[Type text]

'I think that's ... different in the community and the inpatient unit because in the inpatient unit I wouldn't ask somebody necessarily about their pain because that's what the doctors are doing or the nurses are doing ...whereas at home (.) and you have this (.) I think it's you know when you're going in as a sole professional (.)' (P4AC2)

'But if we're going to use [POS-s] as a tool all the time so for every patient we see ... do you think we should be asking them about nausea and all those things (?) Cos that's what we'd have to do if we were using it wouldn't we (?)' (P3 AC2)

The group members recognised, however, that it may be preferable to apply a measure that would not burden patients:

'Now that [TOMs] you could do away from the patient because ... you wouldn't want to go in at that final stage and oh "what an awful (.) have you got there" (.)' (P8AC2)

The participants perceived that an AHP completed outcome measure should neither increase patient burden, nor exclude profoundly unwell patients. Patient-centred outcome measure (PCOM) is a term used by Etkind et al (2015), to allow proxy

[Type text]

measures alongside PROMs. This is relevant, because supportive care aims to help patients and families, rather than increase burden.

The group members used outcome measures to evaluate structured symptom management interventions such as acupuncture, and breathlessness management. They reflected that TOMs may be a helpful addition to the outcome measures already used. This is because TOMs appeared to identify effectiveness of interventions even when patients had deteriorating health:

‘so the impairment score goes down but then the participation score goes up’
(P8AC2)

The TOMs palliative care impairment scale includes symptoms such as pain, breathlessness and fatigue (Enderby and John 2015). However, one group member questioned whether TOMs could identify the severity or frequency of symptoms:

‘I think where I was coming from was that you can’t differentiate can you with these scales they don't differentiate between the people who have the constant level and the people who have the intermittent severe level ...’ (P5AC2)

The group questioned the content validity of the TOMs impairment scale, which required further discussion. Bausewein et al (2015) recommended that measures should be psychometrically sound. The TOMs palliative care outcome scale was

[Type text]

developed by a specialist palliative care AHP team (Johnson et al 2015). **Its** creators acknowledge that it was only tested with eight patients and is under development (Johnson et al 2015). However, the TOMs core scale validity has been established in a large study examining intermediate care services (Ariss et al 2015). As the participants in this action research had not yet tested the TOMs palliative care scale in practice, or consulted with patients for their views **it** ~~this~~ was agreed that this needed to be the next step.

Facilitators to introducing an outcome measure in a palliative care setting.

It is known that action research can create enthusiasm to address problems of concern (Waterman et al 2001; Stringer 2014). This study itself motivated the group members to explore outcome measurement in their setting. However, it must be acknowledged that their interest did not translate into evenly shared personal action between the focus groups. Waterman et al (2001) identified that participants may have different levels of commitment. The first author, who was involved in the action cycles, also had a management role which may have encouraged participant attendance, but not necessarily commitment. An extract from the researcher-participant's reflective diary exposed this issue:

'I was disappointed but not surprised that I was the only person who was prepared with a case study... It showed that although 'action' in action research is thought to be a group responsibility, in fact it was seen to be my job as researcher ...'

[Type text]

Having said that, as the group's knowledge increased, so did **their** enthusiasm. They noted and discussed attributes of particular outcome measures, and made preparations to test the outcome measure that they selected. Such debate is understood to lead to deep collaboration (Somekh 2006). The group's growing knowledge of specific outcome measures encouraged them to explore their uses. For example, one participant identified that TOMs can measure carer wellbeing:

'... for example ... that patient would have said "there isn't a problem" ... whereas ... with the carer distress that would be coming up very highly even though his wasn't and his you know (.) it would show that there was a disparity (.)' (P4AC3)

Somekh (2006) ~~referred~~ refers to 'actionable knowledge,' going beyond description and theory to working together to change practice (p.27). The example above showed that the action research experience developed understanding of the potential worth of the outcome measure. An increase in the perception of value has been found to be a facilitator to using outcome measures (Duncan and Murray 2012; Antunes et al 2014). Therefore action research projects such as this, which actively involve therapists, may help to counter their reluctance to use outcome measures.

Palliative rehabilitation is about living with dying, rather than recovery. The group recognised that as rates of decline vary, goals can rapidly move from restorative to

[Type text]

palliative, that is, change according to irreversible changes in function, coined 'habilitation' (Tiberini and Richardson 2015, p.4). They agreed that PCOMs must reflect the quickly changing situation, and therefore be repeatable as required, and quick to administer. They agreed that minimum documentation time would encourage use of an outcome measure. These findings, concerning timing and speed of administration, have been themes in previous studies, not just within palliative care (e.g. Duncan and Murray 2012).

Concern about the cost of using and learning about outcome measures was also an issue in this study. Funding restrictions and the high costs of measures have been identified as barriers to outcome measurement in systematic reviews (Duncan and Murray 2012; Antunes et al 2014). Duncan and Murray (2012) concluded that organisations ought to offer resources to encourage adoption of routine outcome measurement, but this may be a problem. A recent report found that two thirds of hospices have had statutory funding frozen or reduced (Hospice UK and Together for Short Lives 2015), which for some has resulted in service restrictions. Once again, the unique position of a charitable organisation providing health services, may be relevant when selecting an outcome measure.

Finally, the group acknowledged that the organisation would need to endorse outcome measure implementation, with managerial and technical support for the selected outcome measure. It was ~~acknowledged~~ **recognised** that discussions with managers would raise awareness of the AHP's distinct requirement to measure participation, garner support for a change in practice, and ensure administrative

[Type text]

support. It was recommended that the appointment of a coordinator might ensure such aspects of implementation (Antunes et al 2014).

Implications and limitations

The primary theme that emerged from the data analysis **was** is that there continues to be a discrepancy between the mandate to occupational therapists' and physiotherapists' to use outcome measures and their practice. Whilst the reasons for this discrepancy could be determined (objective 1) addressing those issues was not so easy (objective 2). In this action research study the AHPs successfully produced a plan to test an outcome measure they had selected, within a hospice setting, but they were not able to develop this plan further. This is because the study only included therapists, not service users or managers, so it did not have the authority to test the selected outcome measure in practice. This was a limitation of the study. Whilst including stakeholders from the outset may have advanced the study it may also reflect that AHPs need time to discuss outcome measures, i.e. to learn about, discuss and critique outcome measures, before they are able to act.

Conclusion

This study aimed to explore the process of introducing outcome measures into a practice setting; action research was used because it is an approach to research designed to help the practitioner evaluate and modify their practice. Action research supported the participating AHPs to understand the challenges of using outcome

[Type text]

measures in the setting where they worked. The study showed that a gap existed between AHPs' knowledge and practice but the opportunity to learn, discuss and critique enabled them to select the outcome measures to use in practice as well as to support them to take action to instigate the use of outcome measures. This study also found that rehabilitation within palliative care, where people have life-shortening conditions, provides challenges and opportunities for AHPs seeking to measure participation but that it is possible to measure more than symptoms. This study suggests that clinicians, given protected time to consider the requirements within their clinical setting, could choose and critique selected outcome measures that have clinical utility in the practice setting. **Whilst the findings are specific to a palliative rehabilitation service in England, they may also be applicable to other settings.** Other rehabilitation services seeking to measure effectiveness should consider providing the time needed to learn about, discuss and critique outcome measures so that they can evaluate and select (an) outcome measure(s) with clinical utility in the setting where they work. Different specialities have different challenges and concerns; it is important to be cognisant of particular issues for a speciality when selecting and implementing outcome measures in practice.

Implications for practice

Key findings A clinical speciality's discrete characteristics influences the process of selecting outcome measures.

Action research offers a deep learning opportunity and process that supports rehabilitation professionals uptake of outcome measures.

[Type text]

What the study has added Measuring the impact of rehabilitation in palliative care can move beyond symptom management, and action research can be useful tool to support AHPs to select and implement outcome measures.

Figure 1: The three cycles of action that evolved in this study

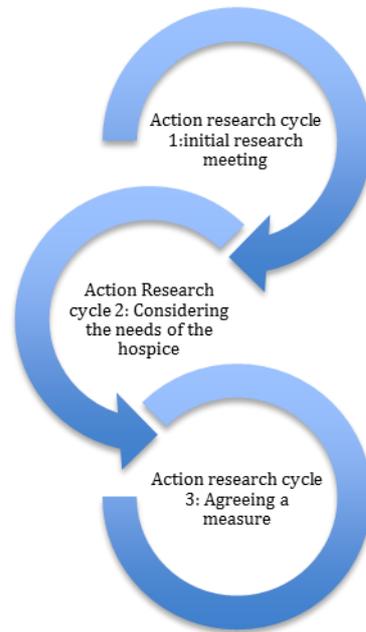


Table 1 – summary of the action research meetings

Action research cycle one
<ul style="list-style-type: none"> • Discussion points: <ul style="list-style-type: none"> - what outcome measures are and what they can do, - opinions of outcome measurement specifically within palliative care , - the potential barriers, and facilitators, to using outcome measures at the hospice, - which outcome measures the AHPs used. For example, at times, they used numerical rating scales, visual analogue scales and POS. - other outcome measures not used to date, for example, GAS and COPM. - what they wanted an outcome measure to be able to achieve. • From their ideas, the AHPs created a list of requirements of an outcome measure for use in their setting. • The AHPs wanted to learn more about POS and TOMs.
Action:
<ul style="list-style-type: none"> • The participants decided to seek more information about POS and TOMs for the next meeting. • The lead researcher was to attend a TOMs workshop prior to the next action research meeting.

Action research cycle two
<ul style="list-style-type: none"> • Discussion points: <ul style="list-style-type: none"> - A clarification from the AHP who used POS that they used POS-Symptoms (POS-s) rather than POS. - The lead researcher summarised the key learning points from the TOMs workshop. - To what extent the outcome measures they had investigated and used met their list of the outcome measure requirements (see table 2). They marked each outcome measure with a yes / no / unsure - the AHPs agreed TOMs and POS-s met the highest number of their requirements.
Action:
<ul style="list-style-type: none"> • Each AHP agreed to prepare a patient scenario to discuss at the final action research meeting.

Action research cycle three
<ul style="list-style-type: none"> - The AHPs selected two patient scenarios, from differing AHPs. - One AHP discussed their case scenario. - Each AHP rated their opinion of the utility of TOMs and POS-s in relation to that case scenario using a 5 point likert scale (see box 1) - The AHPs repeated the process for the second case scenario. - The AHPs agreed that each outcome measure had different qualities. Neither outcome met all of the outcome measurement requirements. - The AHPs agreed that TOMs was the best measure of participation from the outcome measures they discussed.

- | |
|--|
| - The AHPs decided to try TOMs, on a small scale, to learn more about its utility and value. |
|--|

Action:

- | |
|---|
| <ul style="list-style-type: none">• The lead researcher presented a plan to the hospice quality, innovation, productivity and prevention group (QUIPPS) for the AHPs to instigate the use TOMs with twenty patients, and then review its use.• QUIPPS approved the plan. |
|---|

Box 1: The group members' criteria for assessing the value of an outcome measure for use in palliative care

The preferred outcome measure should:

- measure symptoms 1 2 3 4 5
- measure psychological adaptation 1 2 3 4 5
- measure function 1 2 3 4 5
- measure participation 1 2 3 4 5
- be user-friendly for people with cognitive impairment 1 2 3 4 5
- be easy to learn 1 2 3 4 5
- be easy to administer 1 2 3 4 5
- be quick to administer with flexible learning 1 2 3 4 5
- offer clear results 1 2 3 4 5

References

1. Antunes B, Harding R, Higginson I (2014) Implementing patient-reported outcome measures in palliative care clinical practice: A systematic review. *Palliative Medicine*, 28(2), 158-175. doi: 10.1177/0269216313491619
2. Ariss S, Enderby P, Smith T, et al (2015) Secondary analysis and literature review of community rehabilitation and intermediate care: an information resource, *Health Services and Delivery Research*, 3(1). doi: 10.3310/hsdr03010
3. Austin C, Clark C (1993) Measures of outcome: for whom? *British Journal of Occupational Therapy*, 56(1), 21-24.
4. Backman C (2005) Outcomes and outcome measures: measuring what matters is in the eye of the beholder. *Canadian Journal of Occupational Therapy*, 72(5), 259-261.
5. Bausewein C, Daveson B, Currow D, et al (2015) EAPC White Paper on outcome measurement in palliative care: improving practice, attaining outcomes and delivering quality services: recommendations from the European Association for Palliative Care (EAPC) task force on outcome measurement. *Palliative Medicine*, 1-17. doi: 10.1177/0269216315589898
6. Brant A, Pilegaard M, Oestergaard L, et al (2016) Effectiveness of the "Cancer Home-Life Intervention" on everyday activities and quality of life in people with advanced cancer living at home: a randomised controlled trial and an economic evaluation. *BMC Palliative Care*, 15(10), 1-11. Accessed on 22 July 2018
7. Carey H, Roberts D, Pike J (2013) To do or not to do? Advising level of 'doing' in MND. 25th International Symposium on ALS/MND, Brussels, 5-7 September 2014. Available at: <http://www.mndassociation.org/wp-content/uploads/2015/02/wips-final-document-051114.pdf>
Accessed on 5 September 2015.
8. Chartered Society of Physiotherapy (2012) Quality assurance standards for physiotherapy service delivery. London: CSP.
9. Cicely Saunders Institute (2012) Palliative Care Outcome Scale. Available at: <http://pos-pal.org/maix/>
Accessed on 6 February 2015.
10. College of Occupational Therapists (2013) Position statement: Occupational therapists' use of standardized outcome measures. Available at: <http://www.cot.co.uk/position-statements/occupational-therapists%E2%80%99-use-standardised-outcome-measures>
Accessed on 22 February 2015.
11. College of Occupational Therapists (2015) Motor Neurone Disease 2. Assessment and Outcome Measures. Available at: <https://www.cot.co.uk/docs/briefings/older-people-and-long-term-conditions>

Accessed on 25 August 2015.

12. Duncan E, Murray J (2012) The barriers and facilitators to routine outcome measurement by allied health professionals in practice: a systematic review. *BMC Health Services Research*, 12(96), 1-9. Available at: <http://www.biomedcentral.com/1472-6963/12/96>

Accessed on 1 February 2015.

13. Enderby P, John B (2015) *Therapy Outcome Measures for Rehabilitation Professionals*. 3rd ed. Chichester: Wiley.

14. Etkind S, Daveson B, Kwok W et al (2015) Capture, transfer, and feedback of patient-centered outcomes data in palliative care populations: does it make a difference? A systematic review. *Journal of Pain and Symptom Management*, 49(3), 611-624. doi: 10.1016/j.jpainsymman.2014.07.010

15. Eva G, Morgan D (2018) Mapping the scope of occupational therapy practice in palliative care: A European Association for Palliative Care cross-sectional survey. *Palliative Medicine*, 32(5) 960-968.

Accessed on 22 July 2018.

16. Evans C, Benalia H, Preston N et al (2013) The selection and use of outcome measures in palliative and end-of-life care research: The MORECare international consensus workshop. *Journal of Pain and Symptom Management*, 46(6), 925–937. doi: 10.1016/j.jpainsymman.2013.01.010

17. Health and Care Professions Council (2013a) *Standards of Proficiency: Occupational Therapists*. Available at: www.hcpcuk.org/assets/documents/10000512Standards_of_Proficiency_Occupational_Therapists.pdf

Accessed on 5 June 2015.

18. Health and Care Professions Council (2013b) *Standards of Proficiency: Physiotherapists*. Available at: http://www.hcpc-uk.org/assets/documents/10000DBCStandards_of_Proficiency_Physiotherapists.pdf

Accessed on 5 June 2015.

19. Help the Hospices (2014) *Defining quality in hospice care*. Available at: <http://www.ehospice.com/DesktopModules/GalleryServerPro/gs/handler/getmedia.ashx?moid=10055&dt=2&g=1>

Accessed on 5 May 2015.

20. Hemmingsson H, Jonsson H (2005). The issue is: an occupational perspective on the concept of participation in the international classification of functioning, disability and health: some critical remarks. *American Journal of Occupational Therapy*, 59, 569–576.

21. Hicks C. (2009) *Research methods for clinical therapists: applied project design and analysis*. 5th ed. Edinburgh: Churchill Livingstone/Elsevier.
22. Hospice UK and Together for Short Lives (2015) *Commissioning and statutory funding arrangements for hospices in England Survey results 2015*. Available at: http://www.togetherforshortlives.org.uk/assets/0001/1502/Hospice_commissioning_and_funding_survey_results_2015.pdf
Accessed on 30 October 2015.
23. Johnson J, Rice S, McCord J et al (2015) *Palliative care services*. In P Enderby, A John. *Therapy outcome measures for rehabilitation professionals*. 3rd ed. Guildford: J&R Press, 84-85.
24. Krasny-Pachini A, Hiebel J, Pauly F et al (2013) *Goal attainment scaling in rehabilitation: a literature-based update*. *Annals of Physical and Rehabilitation Medicine*, 56, 212-230. doi: 10.1016/j.rehab.2013.02.002
25. Larsson-Lund M, Nyman A (2017) *Participation and occupation in occupational therapy models of practice: a discussion of possibilities and challenges* *Scandinavian Journal of Occupational Therapy*, 24(6), 393-397.
26. Miles M, Huberman AM, Saldaña J (2014) *Qualitative data analysis: a methods sourcebook*. 3rd ed. London: Sage.
27. Pearson E, Todd J, Futcher J (2007) *How can occupational therapists measure outcomes in palliative care?* *Palliative Medicine*, 21, 477-485.
28. Poulsen A, Zivani J, Kotaniemi K et al (2014) "I think I can": measuring confidence in goal pursuit. *British Journal of Occupational Therapy*, 77(2), 64-66.
29. Rudestam K, Newton R (2015) *Surviving your dissertation*. 4th ed. London: Sage.
30. Smith T, Edwards A (2011) *The route to success in end of life care: achieving quality for occupational therapy*. London: College of Occupational Therapists.
31. Somekh B (2006) *Action Research: a methodology for change and development*. Maidenhead: Open University Press.
32. Stringer E (2014) *Action Research*. 4th Ed. London: Sage.
33. Tiberini R, Richardson H (2015) *Rehabilitative palliative care: enabling people to live fully until they die: a challenge for the 21st century*. London: Hospice UK
34. Unsworth C, Duncombe D (2014) *AusTOMs for Occupational Therapy*. 3rd ed. Melbourne, Victoria: La Trobe University.
35. Waterman H, Tillen D, Dickson R et al (2001) *Action research: a systematic review and guidance for assessment*, *Health Technology Assessment*, 5(23), 111-157.

36. Witt J, Murtagh F, de Wolf-Linder S et al (2015) Introducing the outcome assessment and complexity collaborative (OACC) Suite of Measures. Available at: www.kcl.ac.uk/lsm/.../Studies-OACC-Brief-Introduction-Booklet.pdf

Accessed on 1st August 2015.

37. Wosahlo P, Maddocks M (2015) Benchmarking the provision of palliative rehabilitation within the hospice setting, *Palliative Medicine*, 29(5), 477–478. doi: 10.1177/0269216314564240