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Care Planning Meetings with Older People: Issues for Policy, Social Work Practice and Patient Participation

Symposium on Decision-Making Practices in Gerontological Social Work
ESWRA 2019, Leuven

Dr Sarah Donnelly, Assistant Professor of Social Work, School of Social Policy, Social Work and Social Justice, University College Dublin
Origins and Purpose of Care Planning Meetings (CPMs)

- Used more frequently to determine care plans for older people, without:
  - any particular protocol for these meetings
  - consistency about the participation of the patient (Donnelly et al. 2012; 2013).

- Are older patients intentions / wishes maximised?
- How to balance role/input of family caregivers and wishes of older person? (Efraimsson et al. 2004)
Legislative and Policy Context

- Assisted Decision Making Capacity Act, 2015 IRL
- Mental Capacity Act 2005 UK
- UN Madrid International Plan of Action on Ageing (2002) emphasises the need to include older adults in autonomous decision-making processes.

- UN Convention on the Rights of People with Disabilities (CRPD), ‘persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life’ (Article 12).
‘...involves a number of family members, the patient and the hospital personnel in discussions concerning the patient’s illness, treatment and plans for their discharge or their care outside the hospital’ (Hansen, 1998:32.)

- Forum is intended to encourage active participation and empowerment of older people and their families in decision making, doubts exist as to whether they effectively carry out this role (Efraimsson et al., 2004; 2006).

- PWD are more frequently excluded from decisions about their future care (Larsson & Olsterholm, 2014).

- A major reasons for non-involvement is the lack of opportunity to be involved or that there were few or no choices made available to them (Smebye, Kirkevold & Engedal, 2012).
How Are People with Dementia involved in Care-Planning and Decision-Making? An Irish Social Work Perspective (Donnelly, O’Brien, Begley and Brennan, 2016)

◊ Of those clients who had dementia, 55% were reported to be involved in decision-making.

"The elephant in the room is around capacity...the current approach is too simplistic and the current system is not fit for purpose...there is no concept of functional capacity at the moment and everything is very medically led. When they don’t have capacity they’re not really involved and if they are, it tends to be tokenistic" (Community social worker, A19)
Reasons for non-involvement

- Deemed not to have capacity 62%
- Communication difficulties 12%
- Person didn't wish to be involved 10%
- Physically unwell 9%
- No opportunity given 4%
- Family resistance 3%
Current system not seen to support autonomy

“The elephant in the room is around capacity...the current approach is too simplistic and the current system is not fit for purpose...there is no concept of functional capacity at the moment and everything is very medically led. When they don’t have capacity they’re not really involved and if they are, it tends to be tokenistic”

(Community social worker, A19)
Lack of standardised practices

Lack of awareness by HSCPs about need to facilitate supported decision-making

Reliance on families to provide the care and support the person with dementia needs to execute decisions based on their will and preferences

Families and HSCPs accepting a person’s right to make unwise decisions

Prioritising of institutional objectives for example, hospital discharge
What are the mechanisms that support healthcare professionals to adopt assisted decision-making practice? A Rapid Realist Review

(BMC Health Services Research: Davies, Frattori, O’Donnell, Donnelly, Ni She, O’Shea and Kroll, 2019. Forthcoming)

**Assisted Decision-Making Implementation in Healthcare practice: Initial Programme Theory (IPT)**

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<thead>
<tr>
<th>Guiding principle 1</th>
<th>Personalisation of Health - ADM Service Provision</th>
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<td>Health systems that embed ADM as a core principle of person-centred care (C), into a formal service (R), normalise care planning practice (M) and maximise individuals’ autonomy and capacity to participate in decisions about their health and care (O).</td>
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<th>Guiding principle 2</th>
<th>Culture &amp; Leadership</th>
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<td>Health Systems where ADM is a prioritised shared vision (C), influence positive ADM culture (M), and when it is enabled by senior leadership and an adequately funded implementation strategy (R), it fosters commitment, accountability, and engagement across the whole organisation (M) and ADM is implemented and normalised into practice (O).</td>
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<th>Guiding principle 3</th>
<th>Environmental &amp; Social Re-Structuring</th>
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<td>Healthcare Systems with environments that support assistive decision making and interdisciplinary person-centred practice (C), provide appropriate support (R), promote trust and confidence (M) and invite patient participation in decision making about health and social care (O).</td>
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<th>Guiding principle 4</th>
<th>Education &amp; Training &amp; Enablement</th>
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<td>Health systems that have a strong learning culture (C) and invest in public guidance and staff interdisciplinary education and training (R) foster positive knowledge, attitudes and skills (M) leading to confident practitioners and empowered public that engage ADM (O).</td>
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Knowing the patient and the quality of the therapeutic relationship

- A fundamental antecedent to meaningful participation of older people in CPMs is the nourishing of a therapeutic relationship by professionals (Cahill, 1996; Tutton, 2005; Donnelly, 2012; Donnelly, Begley and O’Brien, 2018).

- For genuine therapeutic alliances to occur between older patients and MDTs, trust and respect are vital and an emotionally secure environment must exist, if participation is to take place (Ashworth et al. 1992).

- Knowledge of life world of older person critical (Rämgård, Blomqvist and Petersson, 2015).
How the creation of meaning is achieved in CPMs relies predominantly on the ability of the other participants to involve and help support the older person (Sundin & Jansson, 2002).

Effective communication and decision-making between patients, families and MPTs requires time, training and higher clinician competency in shared decision-making has been evidenced in CPMs of longer duration (Milte et al. 2013).
Aims and outcomes of CPMs are not always apparent, clear or consistent (Loupis and Faux, 2013).

Older people tend not to be prepared for meetings and often lack essential knowledge about the CPM decision-making process and future care options, contributing to reduced opportunities for participation (Efraimsson et al., 2006; Donnelly, 2012; Donnelly, Cahill and O’Neill, 2017).

The function and purpose of the CPM has been fully explained to the older person and their family (Bangsbo et al., 2014).

In order to promote the voice of the older person within their CPM, assistance should be provided to the older person to prepare questions (Bangsbo et al., 2014) or a question prompt list should be drawn up (Milte et al., 2015; Donnelly, 2012).
Formal rules and the overuse of technical language tend to confound and prevent opportunities for dialogue and empowerment (Efraimsson et al., 2004; 2006; Satterlund Larsson 1989).

MDT members tend to control discussions and steer the focus of the CPM to their own, or the institutional agendas (Opie, 1998; Donnelly, 2012).

Negative positioning of PWD (Leppanen & Lindstrom, 1999).

It is not uncommon for older patients to be talked about, in the third person, rather than talked to during their CPM (Hedberg et al. 2007; Donnelly et al., 2012). MDT dominance.

The way that decisions are framed, and by whom, may also have a significant impact on how such information is processed and used by decision-makers (Hedberg et al., 2007).
Impact of Family Members

- Balancing patient and family member participation and difficulty of achieving this in practice (Donnelly, 2012; Donnelly, Begley and O’Brien, 2018).

- Inverse relationship between older person and family member participation; where family participation is high, participation of the older person low (Abramson, 1998).

- Family members are routinely accepted as the key decision-makers (Larsson & Osterholm, 2014) who often fail to acknowledge the wishes of PWD as expressed earlier in the illness trajectory (St-Amant et al. 2012).

- Often the case that MDTs may place excessive demands on family caregivers resulting in the older person feeling like a burden (Bangsbo et al., 2014).
‘...there’s no point in bringing the patient along for lip service’

- Shorter inpatient stays and working conditions of MDTs (Drystand, 2015): planning for rather than planning with the older person (Perry, Hudson & Ardis, 2011; Connelly et al., 2009).

- Physical involvement does not necessarily guarantee genuine patient participation.

- Discrepancy between ideological intention and actual realisation within CPM’s (Donnelly et al. 2012)
Care Planning Meetings

What is a Care Planning Meeting?
It is a meeting to make plans for your future care.

Who will be attending my Care Planning Meeting?
You, as the patient, your family/carers, doctors, nurses, social workers and therapists. As far as possible, we will let you know in advance who will be attending.

Do I need to invite all of my family to my Care Planning Meeting?
It is your decision who, if anyone, you would like to attend your Care Planning Meeting e.g. family member, friend, neighbour, carer, etc.

How long will my meeting last?
Care Planning Meetings usually last between 30mins-1hr.

Where will my meeting take place?
A meeting room will be arranged within the hospital.

Who will arrange my Care Planning Meeting?
Your hospital social worker will arrange your meeting

What will happen during my meeting?
You and your family/carers can ask any questions that you might have.

We would encourage you to think of any questions you may want to ask during the meeting.

Members of the team who are involved in your care will give updates on your progress.

Information and choices will be given about your future care needs.

We will help you and support you if you need to make any important decisions about your future.

It is your meeting
Maximising Participation

- All older people should be afforded the opportunity to participate.
- A follow-up discussion should take place with the older person where a verbal and written information on the CPM is provided and the older person has an opportunity to voice any questions relating to their CPM.
- The older person should be encouraged to identify any issues/topics they would like to be discussed during their CPM and to write down any questions they would like to ask/would like to be asked, on their behalf during the meeting.
- Use of scaling questions/diagrams can be helpful in eliciting the importance of an issue to an older person and may be a useful tool to help determine their wishes prior to the CPM taking place.
All older people should be given the option to participate.

CPM’s should be used in a proactive way so that issues are anticipated and addressed before they reach a crisis level.

Consider the number of people attending CPM.

Use simple, clear language and avoid the use of medical or other technical (discipline specific) language.

Skilled facilitator.

Use the ‘teach back method’.

Strive to maintain a conversational style /dialogue format that is two-way.

Tailor Information!

Avoid usage of the third person grammatical.

Maintain good eye contact and turn to face the older person when you are speaking to them.
In order to ensure meaningful participation of those with cognitive or communication difficulties, additional consultation time within the CPM may be required in order to ensure shared-decision making occurs (Milte et al. 2013).

Need to educate HSCP’s on how best to invite older people to be conversational partners in CPM’s so that their ability to participate is maximised.

Importance of ‘meaningful participation’ which is effective and successful for each older person and not tokenistic in nature.

Definition of participation should be broadened so that it corresponds with the International Classification of Functioning, Disability and Health’s (WHO, 2001) definition, which stresses the sharing of knowledge, communication, and interpersonal relations (Eldh, 2010).
‘...the skill and effort that we put into our clinical communication does make an indelible impression on our patients, their families and their friends. If we do it badly, they may never forgive us; if we do it well they may never forget us’ (Buckman, BMJ 2002)
Thank You for listening!

Questions?