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Older people in mental health care.

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Specialist mental health services for older people are a relatively new development. In the UK for example, such services were introduced only 20 years ago. Prior to this a need for such services was not recognised as later life mental illness was seen as an inevitable part of ageing and incurable<sup>1</sup>. This was illustrated in the diagnostic and classification manual which in 1952 indicated that adjustment reaction of later life (over 65) and 'senile dementia' were the only diagnosis available for older people<sup>2</sup>. From around the 1940's various psychiatrists in the US and the UK were challenging such views and arguing that dementia was not an inevitable part of ageing and that other mental health problems could be experienced<sup>1</sup>. A sufficient body of evidence had not been enough to convince the psychiatric community of this until 1980's when the DSM III-R<sup>3</sup> included for example that the diagnosis of schizophrenia could be given to people in late adult life.

Despite this, some progress had been made in service provision and from the 1950's a number of individual hospitals introduced day centres and other specialist services for older people with mental illness, but there was no national policy coordinating such developments and indeed it was discouraged<sup>4</sup> Scotland was the first place to open a specialist unit for joint assessments between psychiatrists and geriatricians<sup>1</sup>.

Old age psychiatry eventually became a separate speciality in the UK in 1988<sup>5</sup>. However, due to the history behind such developments, classification of mental illness had been investigated with people in younger age groups and as Beekman et al<sup>6</sup> note, understanding of the symptoms of clinical depression had not been developed in the context of older people with the accompanying complexities and implications of ageing processes and physical illness or both. This remains an ethical issue where complex diagnoses are being applied to people for whom they have not been developed. In the clinical literature factors that influence how depressive disorder presents in old age have been highlighted which include overlap of physical and somatic symptoms and minimal expression of sadness<sup>7</sup>.

Many countries have little specialist help for older people with mental health problems<sup>8</sup> and de Mendonça Lima et al<sup>9</sup> found that only 66 per cent (n=11) of the seventeen countries surveyed in Europe had specialist services for older people and only 10 percent (n=2) taught old age psychiatry. They report that the World Health Organisation and the World Psychiatric Association collaborated to highlight the 'limited public and professional awareness of stigma and discrimination related issues with regards to the elderly with a mental disorder' (p679). This situation they regarded as discrimination particularly given the frequency of psychiatric disorders in the people who attend primary care services. They state that '..even for Europe which is in a comparatively better situation in this regards than other WHO regions, programmes and services for elderly persons are under developed'. They argue that stigma against older people combines two sets of interrelating issues; presence of mental disorder and the status of older people in a given society where the lower the social status the higher the stigma.

In their survey, stigma in relation to psychosis was judged to be greatest in contrast to clinical depression and Alzheimer's disease.

So, this is the situation we are in now to varying degrees around the world and it remains the case that some mental health problems are still not recognised for older people in classification manuals, for example eating disorders, despite clinical cases being recognised<sup>10, 11</sup>. The main challenge continues to be discriminatory attitudes and nihilistic attitudes towards older people who need mental health care that prevents equitable and fair services. This is reflected in policy across the international community and a number of consistent themes have emerged in tackling older people's health that include, challenging age discrimination, independence, promoting mental health, healthy living and integrated services<sup>12</sup>. This reflects a population approach to health care that considers the majority of people. Older people in contact with mental health services however, are a minority.

This discussion assumes that we all know who we are referring to when we talk about older people and 65 years of age tends to be used as a cut off for delineating old age. However, from an ethical point of view, this in itself is problematic. In discussing mental health provision should we focus first on the mental health needs or the assumed needs from being 'old'? Mental Health policy certainly in the UK focuses on young people between 18 and 64. There is no comprehensive *mental health* policy for the over 65s as the policy that governs such services is aimed at *older people* as a generic group although rooting out age discrimination has resulted in health services ensuring an

approach that considers need not age<sup>13, 14</sup> and more recently there is an attempt to focus on mental ill health in different adult age groups in one document<sup>15</sup>.

The provision of services by age defined categories ensures an arbitrary focus on chronological age. In working for the good of older people in developing specialist services an inadvertent perpetuation of ‘the other’ has been established even though we now can expect to find at least two generations of people in the over 65 age groups. Those clinical issues recognised as relevant for older people do not become significant only on a persons 65<sup>th</sup> birthday. Research samples regarding older people ranges from 50 years plus, and the Geriatric Depression Scale was developed with people aged 55 and over but tends to be used only with the over 65s, highlighting a variation, in this case between research and practice, in the concept of who older people are. Community services are more and more adopting protocols that enable people who have many years of contact with an adult service to remain with that service into old age instead of being moved into an old age service unless they develop significant physical health problems or dementing illness as recommended by the Royal College of Psychiatrists<sup>16</sup>. However, despite these developments, it is indirect age discrimination such as negative attitudes that is of the most concern for older people accessing health care<sup>17</sup>. One of the main problems identified by the Moots report<sup>18</sup> is the pervasive *care* narratives that accompany services for older people which should be replaced by narratives that focus on *aspirations*. The Department of Health in the UK has published 2 similar documents regarding minimum standards for care homes, one concerning ‘adults’<sup>19</sup> and one concerning ‘older people’<sup>20</sup>. The one for ‘older people’ has removed reference to aspirations, a telling omission.

Most health care for older people takes place in primary care and people over 65 years of age constitutes the majority users of health services<sup>21</sup> due to older age being a risk factor for a number of physical illness and also arguably due to the accumulation affects of lifestyle choices over the years. The complexities in relation to older peoples mental health is demonstrated in part through the relationship between physical and mental health problems. These issues are further compounded by the social context of individual's lives. The UK inquiry into mental health and wellbeing in later life<sup>22</sup> identified discrimination, participation in meaningful activity, relationships, and poverty as the five main areas that influence mental health and well being in later life. Similarly, NHS Scotland<sup>23</sup> found older peoples priorities to be; family and friends, positive attitudes, keeping active, maintaining capability and independence, and negotiating transitions.

The experience of older people with mental health problems is made more challenging due to the fact that amongst older people there are low detection rates for mental health problems<sup>24</sup>. Rates for people living in care homes are thought to be underestimated<sup>25</sup> and of older people found in general hospital care, over 60 per cent have mental health problems in UK<sup>26</sup>. In addition, one survey found that 25 per cent of homeless people in London are over 50 years of age and half of these have mental health problems, half have alcohol problems and half have physical health problems<sup>27</sup>. Homeless people are not usually registered with a GP so this part of the population is largely invisible. Thus, the sophisticated mental health provision discussed in mental health policy excludes people who fall into different special consideration. That is, if you live in a care home

your health issues may be served by a GP, although you may have access to some specialist mental health support. If you are homeless, you are likely to access services for homeless people rather than for older people. If you are in prison, you are not likely to have your mental health problems addressed particularly if you are older<sup>28</sup>, and people over 60 constitute the largest growing population of people in prison<sup>29</sup>. For individuals (of any age) who develop types of dementing illnesses (of which there are several hundred), these are not automatically considered complex health care needs according to the care quality commission criteria for registration for care homes<sup>30</sup>. However, approximately 66 per cent of care home residents have a dementia<sup>31</sup>.

The continued problems faced by older people in health services justify the need for a separate age classified chapter. We are not however focusing exclusively on reduced mental capacity issues, an issue that seems too often assumed to be of primary relevance to older people, whereas it can be relevant to people of all ages. We make reference to this to illustrate where it can be wrongly assumed to be the only mental health issue of concern on the basis of beliefs about older people.

In 1991 Barrowclough and Fleming<sup>32</sup> discussed ethical issues in working with older people focusing on decision making and informed consent. Their discussion remains relevant in 2009 and the and slow change from age discriminatory practices is evidenced by continued debate and policy initiatives that attempt to change such practices. Both Beecham et al<sup>33</sup> and the Royal College of Psychiatrists<sup>34</sup> have recently highlighted continued age discrimination in mental health services. Tools that have been

developed since 1991 that aid a more objective approach include the Mental Capacity Act<sup>35</sup> and the Human Rights Act<sup>36</sup>.

Some of the challenges in care provision for older people with mental health problems may result from the continued existence of a paternalistic medical model rather than humanistic model to care service delivery. Paternalistic approaches to care have been well documented as reducing personal control<sup>37</sup> yet at times ethical discussions based on autonomy, beneficence, non-maleficence and justice contribute to the continuation of paternalistic approaches<sup>38</sup>. These traditional ethical values have been found to be inadequate as a sufficient guide for day-to day ethical action<sup>39</sup> and the unique terminology of biomedical ethics can result in it being perceived as a specialist interest subject rather than an everyday accessible issue.

The starting point for the discourse on ethically based care that we are proposing is grounded in the values of the individual whose life the care and ethical decisions relates to (fig 1). This reflects a shift in some aspects of society towards more humanistic approaches to interventions and interactions where the values of the individual whose life the issue relates to, are central to decision making. In mental health care this is illustrated through practice development in relation to contemporary recovery values although this is much less well developed in relation to older peoples services. Alternative approaches to ethics propose a refocus using existential and human advocacy within a relational way of being. These approaches are based on the common humanity of the nurse and the patient<sup>40</sup> and may reduce the risk of paternalistic ethically based care.



The ethical dilemmas inherent in the context of older people necessitate the ability to balance different ethical demands in situations where a blend of principles, rules, virtues, paradigms and narratives is necessary to achieve practical wisdom<sup>41</sup>. We suggest that these features of ethical decision making must be located within the patient-practitioner relationship. This aspect of practical wisdom should be a continuing professional development aim for practitioners who currently base their ethical practice on Codes of Professional Conduct and legislation, as the ‘one size fits all’ approach (universalism) that could result from using such resources to guide decision making may not always result in the optimal care for an older person with mental health problems (individualism). To know how to act ethically, health care practitioners must work towards understanding the other’s perspective and potential vulnerability<sup>40</sup>.

Professional standards are based on certain values and these values, like the society of which care organisations are part are subject to constant change. Practitioners themselves will reflect the values of both the society from which they are drawn and personal interpretations of these. One of the challenges in current health care services is that all too often health care professionals can find themselves navigating against care values of organisations characterised by the paternalistic approach of biomedicine and organisational ethos. Rodney et al<sup>38</sup> found that nurses were working in between their own values and those of their employing organisations, as well as with other competing values and interests. All too often health care professionals can find themselves navigating against care values of organisations characterised by the paternalistic approach of biomedicine and organisational ethos. A study by Nordum et al<sup>42</sup>

highlighted that nurses regarded the system in which they worked as being unethical, not only in its effects on the treatment of older people but also in its dealings with the workforce. It is therefore important to consider the experience of both service users and health care professionals. Austin<sup>43</sup> raises the issue of mental health nurses' moral distress, where nurses gave accounts of lack of resources such as time and staff, lack of respect and absence of recognition for both patients and staff as severely diminishing their ability to provide good quality care.

Health care practitioners have a responsibility to give the best care they can in both non-complex and more challenging situations. In both of these situations it is useful to consider ethics as a practical resource to guide decision making. This would necessitate the acquisition of an everyday ethical vocabulary that can also be shared by older people with mental health problems, their families and carers<sup>44</sup>. One starting point may be a definition such as that provided by Hinman<sup>45</sup> who remind us that at the core, ethics is 'a conscious reflection on our moral beliefs' (p5). However, for practitioners this must be viewed in a context where patients' moral beliefs need to be considered alongside those of health care professions' guidance when delivering care. Hewitt<sup>46</sup> argues that relationship based care that sets aside self interest is an ethical practice that places values before research based evidence.

The type of ethics that can enhance everyday decision making are; practical ethics - thinking about whether an action is right or wrong; normative ethics -using general theories about what is right and good that we can use in practical cases e.g. Codes of conduct; and metaethics - the study of the very ideas of right and wrong<sup>47</sup> and these

concepts can be applied to practice through reflection on the beliefs and values of the individual and the explicit identification and integration of these into care decisions centred on the person concerned.

Applying practical and normative ethics in an everyday sense can be done in the context of relational ethics which emphasises the contextual features of relationships<sup>39</sup> (fig.2). This approach builds on the foundation of previous ethical thinking and focuses on environment, embodiment, mutual respect and relational engagement<sup>48</sup>. Environment explores the organisational system in which care is given and how care relationships are affected by this system. Embodiment recognises that scientific knowledge and human compassion need to be given equal weight and Engagement emphasises the development of an emotional connection between nurses and patients, which recognises both nurse and patient as whole being<sup>48</sup>. Taking a relational ethics perspective means being sensitive to a particular situation through the opening of a dialogue between individuals and an appreciation of the uncertainty inherent in human circumstances.

Hughes<sup>49</sup> places his ethical discussion about old age psychiatry away from theorizing and firmly from the perspective of the person and emphasises that clinical decisions such as whether a patient should be told a diagnosis of Alzheimer's disease, are a matter of value of the families and the practitioners involved. He suggests that we should view people as situated-embodied-agents, which emphasises the importance of both psychological life and the human body within a context of human social relations, culture and history. His example of a person with a cognitive impairment drinking excessive alcohol explores the dilemma where respecting autonomy can mean leaving a

person to 'drink himself to death' and paternalistic action of compulsory detention in hospital arguing that traditional ethical principles may clarify the dilemma but not solve it. Reference to narrative ethics asks us to consider people in the context of their life stories which may offer different solutions such as more effective treatment aimed at root causes of drinking behaviours such as trauma in early life<sup>49</sup>.

The risk that older people who have mental health problems are seen as 'less than' other members of society has been identified as a global problem by the World Health Organisation<sup>50</sup>. This problem becomes less evident where emotional connections are made between people needing and people delivering care. MacDonald and Mallik<sup>51</sup> found that where practitioners develop a sense of common humanity between themselves and patients, the resulting formation of an emotional connection meant that when nurses perceived violations of patients' dignity or rights their own emotional responses were a powerful trigger for advocacy. The development of a sense of common humanity may lead to care that contributes to what Aristotle considered human flourishing and practical wisdom, where human flourishing is the ideal goal of human action<sup>52</sup> an ideal congruent with contemporary recovery values.

Returning to consider one of the moral principles of biomedical ethics, respect for autonomy, it is worth developing such consideration into a discussion of advocacy. Advocacy can be defined as the act of informing a person so that they can make the best decisions for themselves<sup>53, 54</sup>. Advocacy not only safeguards but positively contributes to the exercise of self-determination and this is essential if patients are to identify and engage in achieving their aspirations<sup>55</sup>. There is an important question to consider

however. How can an emotional connection be fostered in environments where nurses may be self protective in stressful circumstances? A sliding scale relationship may be the most practical solution that enables not only a recognition of when nurses are more or less emotionally able to move in and out of this connection, but also enables a visualisation of a sliding scale between autonomy and advocacy where negotiations within relationships recognises each person's strengths and weaknesses on a particular day (fig. 3). A sliding scale relationship between autonomy and advocacy is one of the key features of optimising ethically based care with recognition of the emotional labour involved on all sides. Where autonomous decisions become more problematic, for example in later stages of dementing illness, the ethical challenge should be met by a 'sliding scale' rather than 'all or nothing' approach to decision making, akin to the decision specific framework utilised by the mental capacity act but more flexible and reliant on mutual respect. This approach necessitates sensitive, ethical assessment of individual's needs.

A life context relational approach is illustrated in vignette 1.

### Vignette 1

Jim is a resident of a care home, an older man who experiences mental health problems caused by a dementing illness. Staff had known him for some time and had concluded that he was a violent, aggressive and difficult man. A health care professional visiting from an external organisation had a meaningful discussion with him (though not using fluent or conventional verbal communication skills) about his current situation, how

poor communication between him and the staff resulted in situations deteriorating to conflict. The manager of the home was surprised on hearing this feedback and committed to reflection on how they had reached their conclusions and how these had influenced all subsequent interactions with Jim.

Vignette 1 raises many questions, the most important of which relates to the quality of Jim's life and the need for sensitive and self aware assessments. In a situation that focused on his social life and relationship to others he demonstrated his vulnerability and a willingness to engage in meaningful conversation when some effort is engaged in on the part of the listener. Staff, under pressure to complete their work, acquired no insight into the more vulnerable and sensitive aspects of his personality. Care provision was reassessed by the staff following this experience.

This common everyday situation would not necessarily be seen or experienced as an ethical dilemma but can be considered crucial<sup>56</sup>. Randers and Mattiasson<sup>56</sup> point out that issues such as choices of food bear little resemblance to those which are morally dramatic. One interesting example involves the dilemma of whether to lie or be truthful with a resident in hospital who believes they are waiting for a train. The resident is getting into conflict with a carer who insists he is not waiting for a train, he is in hospital. They argue that another carer who provides a 'fanciful' response (i.e. not the truth), by saying 'why don't you sit in the waiting room (pointing towards the dayroom) and wait until your wife comes. I'll go with you. You can have a cup of coffee while you wait.' He responds: 'That sounds very nice' (p69), maintains the patient's dignity. By understanding their perceptions of threatened integrity; the resident was allowed to

be themselves. The importance of the role of the patient-practitioner relationship in resolving ethical issues is highlighted by Slettebo and Bunch<sup>57</sup> in the use of strategies of negotiation and explanation to resolve ethically difficult situations, which required discussion with and knowledge of the person.

It would be easy to assume in vignette 1 that the Jim was lacking mental capacity. A recent research interview<sup>58</sup> with a staff nurse in a care home was curtailed by the nurse stating that as the unit was not a mental health unit, they did not use the mental capacity legislation. A working knowledge of the tools this legislation offers and its application in Jim's case would ensure an understanding of his ability to communicate autonomous decisions.

Reflecting on the care experience of Jim in vignette 1, different outcomes of care could have resulted had a relational ethics approach been used. Jim explained that when he tried to stand up, staff shouted across the communal lounge 'Sit down you are going to fall', a response possibly guided by risk frameworks, concern for his physical welfare and fear of accusations of neglect. Despite this it was experienced by Jim as a lack of respect which triggered an angry response resulting in him shouting back at the staff, reinforcing the staff perception of him as an aggressive patient. Had an approach based on mutual respect been applied he may have experienced the direction differently, knowing what lay behind their personal concern. A discussion with Jim could have contributed to the development of a new understanding between Jim and the care staff. Similarly applying an engagement approach, the development of an emotional connection between the practitioners and Jim would result in a meaningful

understanding of his experience that recognised both patient and care staff as whole human beings.

Following on from a relational ethics approach to Jim's care further developments in his care could have been achieved by using a sliding autonomy/advocacy approach to decisions about his day to day care. There was no care assessment or provision that related to Jim's aspirations (fig.4). Prior to his declining health Jim had been a physical training instructor and in later years had been involved in local football training. Discussion with Jim soon revealed his aspiration to maintain a connection with these interests. This could have been facilitated with minimal time and financial commitment, by ensuring provision of resources and activities related to local football activities. Where Jim was able to make choices on how he spent his considerable 'leisure time', provision of information on the choices available to him may have resulted in lowering his levels of frustration and an overall improvement in interpersonal relationships.

Use of these approaches could have ensured that Jim's human dignity could have been preserved, his physical and psychological safety could have been maximised at the same time as preventing and minimising harm. This reflects the features of the moral horizon proposed by Rodney et al<sup>38</sup>, the horizon representing 'the good' towards which health care professionals and patients navigate. As a result of not reaching the horizon the resident was left feeling dehumanised, feeling that he was not of value, powerless, unsafe and that he was suffering unnecessarily<sup>38</sup>.



Some situations introduce further complicating issues for decision making. Consider vignette 2.

### Vignette 2

Jack is a 90 year old man, who is blind. He is admitted to an inpatient ward for assessment following questions about his mental state and psychosis. He appears anxious and afraid in this strange place he cannot experience visually and this is maintained over a number of days. Nurses attempt to develop a relationship with him, serve him meals in his room and reassure him. On one occasion they find his room barricaded and the man shouting and sounding distressed inside. They manage to dislodge the barricade, in the process adding to the man's fear. Once inside, he attempts to attack the nurses with a cutlery knife. He brandishes the knife indiscriminately, deliberately and intentionally, shouting threats as he does so and so the nurses retreat. The next few hours are spent attempting to talk through the situation with the man to no avail. Eventually, they reluctantly decide they must restrain him and they bring an end to the incident. He is tearful and apologetic. The staff complete an incident form. The following day, the unit manager demands an explanation as to why a 90 year old blind man was restrained.

It is tempting as a first response to view the action of the nurses in restraining the patient as just wrong as there are potential consequences that might be considered non beneficial and failing to respect autonomy as well as the added physical risks when restraining a person of 90 due to ageing changes in bone density resulting in more easily fractured bones<sup>59</sup>. It must not be presumed that practitioners and patients hold the same

perceptions of ethical issues. For example, in a study across five European countries nurses were found to have more positive perceptions than patients of the realisation of autonomy (all 5 countries) and informed consent (in four of the countries)<sup>60, 28</sup>. Given the reaction of the patient in vignette 2 and the violence he was expressing he may feel it was ethically justified for the nurses to intervene as they did, whilst the nurses are more worried and concerned about their decision. Such discussions are rarely if ever conducted in practice settings.

In vignette 2 the relational approach did not resolve the crisis as their decision to avoid restraint would rely on the alternative which would be to allow the situation to continue indefinitely until he was exhausted, a choice the nurses considered less ethical than physical restraint in this case. The relational framework however, was reinforced later by the emotional engagement stimulated by the patient's tears and the nurse's acceptance of his apologies, an approach that will influence what happens in the future. Their continued respect for him rather than making judgements about his behaviour would be the foundation by which an advocacy-autonomy ethics in the context of the relationship can be then considered. From a life context point of view, Jack was known to be strong, determined person, a former soldier and athlete. Even though the nurses may not have known him well, this information about his life ensured in the short term respect for his personal strengths and an understanding of their relationship to a person with such attributes. In the longer term, their relationship could build on further knowledge of the meaning this had for Jack in his life and this connection could contribute to reducing conflict in stressful circumstances.

There is another issue that needs considering in a different way here. That is the even more complex decision to restrain someone who is 'old' and disabled. The tone of the manager's question implied that it was not acceptable to restrain a 90 year old blind man, with the implicit assumption that it would never be necessary due to how frail and vulnerable such a man must be. A reverse ageism is at work which considers some actions to be unacceptable on the basis of age and disability, rather than need. The impact of such a judgement is that staff in similar situations question themselves, are afraid to make clinically sound decisions for fear of being judged by others based on their beliefs and stereotypes about older people. It adversely affected good decision making rather than improving protection for the patient and others.

## **Conclusion**

The approach to ethically based care discussed in this chapter has four key components: the values of the person/patient and practitioners, the contextual core of the patient-practitioner relationship, a sliding autonomy and advocacy scale and a focus on the person/patient's aspirations (fig 4).

Ethically based care decisions made with older people who have mental health problems must take into account personal values. This requires development of a vocabulary of ethics that is accessible to individuals and people who have a supportive role in their lives. The health care professionals involved in care provision need to be able to reflect on how their values relate to those of the people they are caring for and the organisation

that they are working within. These developments could contribute to a more responsive ethically based approach to care.

From this foundation a sensitive and flexible, sliding scale of decision making could operate which would be responsive to individual's varying needs for autonomy and advocacy. We suggest a greater focus on the aspirations of older people living with mental health problems regardless of the setting, rather than the provision of services that are limited to assessing functional care needs. The fundamental component of this framework to ethics based care is the patient-practitioner relationship, which is the prerequisite of ethics based care decisions. This is offered as an alternative to a paternalistic tick box approach that could result when a purely biomedical ethics approach is used.

The ethical approaches discussed here will be influenced by individual customs and culture. Relational ethics incorporates such differences into its strengths where, rather than worry about whether you are being culturally sensitive, the relationship enables a genuine curiosity about such customs and culture, and an open dialogue about how individual people live their lives. The relationships that inform ethical practice are not unthinking relationships, but well thought out, conscious and reflective and this is where practitioners can focus their efforts. It enables ethically based care needs to be flexible.

This approach to ethics based care however is applicable for any person of any age. We have discussed ethics in this chapter with particular reference to older people as such

people are up against the greatest challenges and those with mental health problems even more so. A life context relational approach offers a way of breaking down these barriers.

Figure 1. Foundation of ethics based care



Figure 2. The relational context of ethics based care

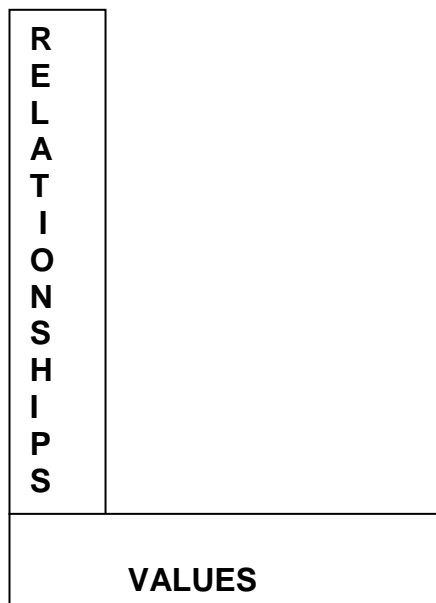


Figure 3. Sliding scale of advocacy and autonomy

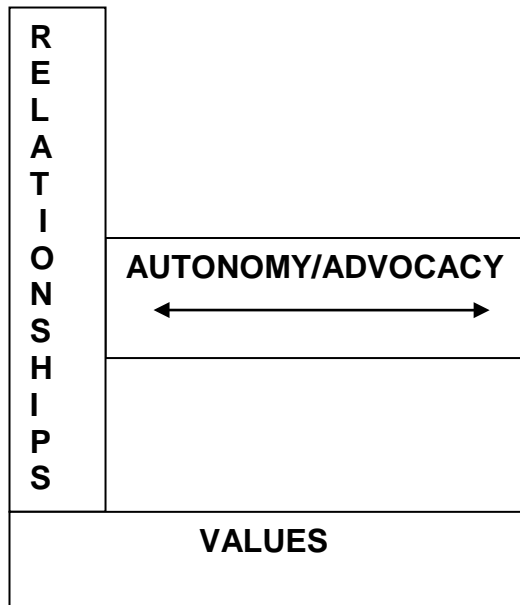
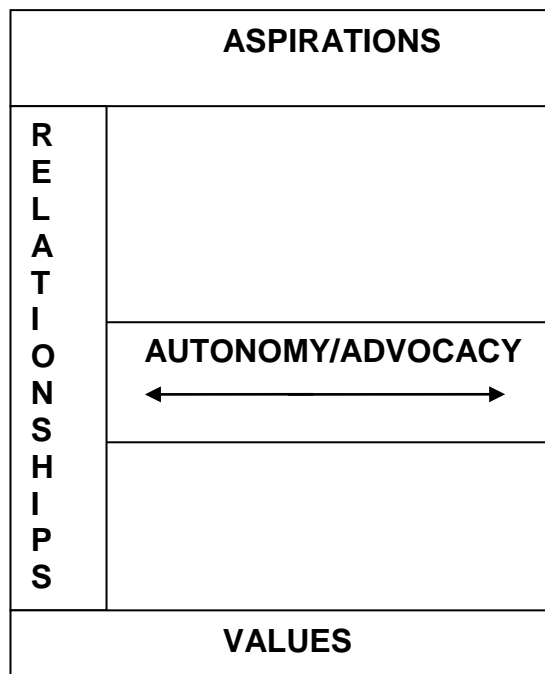


Figure. Four Key concepts in ethics based care



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