What Influences Older People's Decisions about Care and Support?

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Abstract: There are many factors that influence older people's decision making about care and support they want or need in their daily lives. This paper investigates choices and decisions of people age 65 and older who receive paid and/or unpaid care on a daily basis with a focus in Scotland, drawing on a grounded theory framework. The literature review considered what is important to older people about care, support and resource utilisation and examined how decisions are made in relation to these applications. The review identified the ability and opportunity to make choices as a central theme. The key issues important to older people included control, independence and quality of life. Other factors that were found to influence how people make decisions included unmet needs, relationships and availability of informal care. The review found that older people wanted to stay in their homes for as long as possible. Findings suggest that additional research is required about what influences older people in care decisions.

Keywords: aging, choice, decision making, formal (paid) care, informal (unpaid) care, quality of life, grounded theory

Introduction

There are many factors that can influence older people's decision making regarding formal (paid) and informal (unpaid) care and resource utilisation. Older people for the purpose of this article refers to people that are ages 65 and older who need care and support on a daily basis. This paper investigates perspectives on older people's decisions about care and support with a Scottish focus utilising a grounded theory framework. A grounded theory approach was used and is one of the most

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influential theoretical frameworks for organizing and analysing information (Shipman 1997). Grounded theory included organizing data and analysis with early data guiding how the review progressed (Charmaz 2006). The questions asked of the literature included: What is important to older people about care, support and resource utilisation? How do older people make decisions about care, support and resource utilisation?

There is confusion from professionals about vulnerable adults' choices and rights regarding capacity (ability to make independent decisions), levels of control, citizenship rights (with a focus in Scotland for this paper), independence, and human rights versus harm and abuse (Stewart 2011). The wider goals of older people include continued independence, psychological sense of independence or autonomy, and maintaining choice and control (Craig 2004). These wider goals can be in conflict with professionals if perceived to cause harm or puts the person at risk and/or if capacity is in question. However, older people acknowledge that social care and health services are only part of the broader picture that affects quality of life (QoL) (Thornton 2000). As a result, this review investigates both what are important to older people and how they make decisions about care, support and resource utilisation.

This article reports on the methods used in this exploratory literature review. Next, results are discussed. The first question is detailed, *What is important to older people about care, support and resource utilization?* Key findings included choice, control, independence and QoL. Then, the second question was detailed, *How do older people make decisions about care, support and resource utilization?* Key findings included unmet need, meaningful relationships and informal care.

Methods

Grounded theory uses a discovery approach to identify patterns, themes or categories which lead to a working theory based on findings (Rubin & Babbie 2008). This review took a similar approach.

The basis of inclusion of sources followed a problem formulation (Rubin & Babbie 2008) that led to the proposed research questions and supported the process used in this review. The problem formation (Rubin & Babbie 2008) included: narrowing research questions to a feasible topic, consulting with colleagues,

conducting the review "in light of" previous work (p.134), using suggested databases, strategies of checking bibliographies and utilising the reference library.

A detailed review of the literature review process is listed as Appendix A. This resulted in 114 relevant sources, with a selected range represented in this paper. Searches were conducted using a standard set of search terms. Advice was sought from reference librarians and colleagues who suggested specific search engines and sources. Searches were also made of article reference lists and bibliographies to find pertinent articles. Only articles in English were reviewed and included, all other languages were excluded.

The exploratory search started with a set of search terms (see Appendix A) that related to older people's views of care, support and resource utilisation. ProQuest, Web of Knowledge and the Joseph Rowntree Foundation research website were searched initially and 23 relevant sources were identified and abstracts reviewed that led to QoL findings. Searches within Social Care Online, Social Services Knowledge Scotland, Web of Knowledge, Google Scholar, and Sociological abstracts led to a further 34 sources being identified. This led to informal care as an important finding. Then, Applied Social Sciences Index and Abstracts (ASSIA) were searched along with online searches for specific statistics and demographics for Scotland. Colleagues and reference librarians as well as article bibliographies, reference lists, and literature linked to prior readings were utilised and another 30 articles were identified. Reference librarians were consulted and updated online searches for statistics and government reports and legislation were utilised for 27 total sources utilized for formal care. No new relevant formal care data was found when additional inquiry yielded no new additional information when searched (saturation).

There were challenges when deciding which articles to include and exclude. Inclusion was determined by relevance to research questions, driven by emerging data and followed the problem formulation process. Some research and reports such as Vestri (2007) were not peer reviewed and findings needed to be viewed with caution. There were issues with variations of terminology and differing, subjective meanings for identical terminology. For example, QoL, health and wellbeing did not have universal meanings nor did person centred definitions or active aging. This was also found to be problematic when distinguishing decisions, choice and individual views in the literature. Categorizing concepts using a comprehensive approach for these ideas and concepts assisted in separating these topics that overlap. For example, the use of

mind mapping assisted this process and specific definitions were adopted, narrowing the focus of definitions. Although, topics such as QoL, are subjective and multifaceted and would vary per individual perspective, as expected.

A preliminary diagram seen in Figure 1 illustrates key topics that emerged on decision making for care and resource utilisation, and as additional data became available changes were updated accordingly. This is consistent with the discovery approach (Rudestam & Newton 2007) in grounded theory based on literature findings as the review progressed; categories were restructured and reorganized as additional data emerged. The use of a visual diagram throughout the process was an asset in exploring topics in the literature.
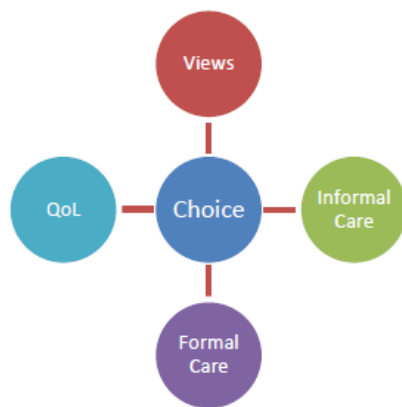

Figure 1. Illustration of Decision Making for Care and Resource Utilisation

Four initial broad topics areas emerged at the start of the review shown in figure 1, choice being a common factor found throughout which will be discussed in the following sections. Additional topics emerged as more literature was reviewed. The four areas included: views of older people about what is important to them in care and support, QoL, formal and informal care. As more data became available, other topics became prevalent. The collective results of the review are explored in additional detail.

Decision Making

Findings revealed that how older people make decisions about formal and informal care and resource utilisation is complex. The Economic Theory of Decision

Making (Edwards 1954; Sanfrey et al 2003) otherwise known as choice theory indicates human behaviour is purposeful and originates from within the individual rather than external forces, with behaviours aimed at fulfilling basic needs (Glasser 1975; Howatt 2001). Choice theory (Glasser 1975) indicates behaviour results from requiring meeting basic needs. These needs include love, power, fun, freedom, recognition, and survival (Howatt 2001). Although, Ware et al (2003) researched basic personal care experiences of older people, reporting quality of care was satisfactory and, '…there was recognition that the quality of life is not always addressed… there is so much more to life than being washed and dressed' (p. 425). This infers people need more than just partial, minimal needs met. Also, numerous things need to happen to facilitate decision making, involving complicated issues.

Several things need to happen prior to decision making and a number of issues come into play. Literature suggests one issue is opportunity. People need the chance to actively engage in the decision making process. Another issue is information to make informed decisions. Reed (2008) found opportunity to make decisions was not sufficient, people must be able to actively participate, 'When decisions are highly technical, this may involve educating participants, developing the knowledge and confidence that is necessary for them to meaningfully engage in the process' (p. 2422). Furthermore, older people and staff reported that accessible information was needed to make informed choices (Glynn et al 2008). Carers and older people reported wanting additional information that is easy to find in a format easily understood (Leadbeater & Lownsbrough 2005). Information also influences how people make decisions and the outcome: having the information to make an informed decision rather than having no, partial or incorrect information or information that is not understood (includes receiving information in a font that is too small to read) affects choice.

Choice (Glynn et al 2008; Ware et al 2003) was a central theme linking both research questions and key findings as people valued the fundamental choice to have a good life. There are specific things that are important to older people with higher care needs to have a good life (Bowers et al 2009). A good life included personal authority, meaningful relationships, personalised care and support, meaningful daily and community life, and home and personal surroundings (Bowers et al 2009). The literature reported other things people valued including: control (Bowers et al 2009; Craig 2004), personal autonomy (Bowers et al 2009), personal identity and self-

esteem (Bowers et al 2009), social participation, feeling part of a wider community, and maintaining identity and independence to uphold dignity are also known to be important to older people (Craig 2004). These will be explored in additional detail.

The key questions are addressed sequentially: 1. What is important to older people about care, support and resource utilization? 2. How do older people make decisions about care, support and resource utilization?

What is Important to Older People about Care, Support and Resource Utilization?

Many considerations influence decisions regarding what is important to people because of resources that may or may not be available to people. This could influence the individual's life, needs, goals, values, and happiness linked to what is available to them, which may constrain or expand their choices.

Opportunities to make preferences known are important to older people. This includes situations when there are no choices; older people still prefer to be asked their preferences as people retain a sense of personal authority and dignity and people want to remain empowered. One example is when an older person cannot complete a task; a decision needs to be made about what to do about fulfilling that need. Older people still prefer to be asked about what should be done, regardless of options which can be seen in programs such as Self Directed Support (Age UK n.d.) where older people can exercise personal choice. This enables individuals to be informed, participate in decisions, even when there may only be one option of allocating physical care of themselves to someone else.

Other considerations in making decisions are reported to depend on a number of influences. Older people identified personal characteristics (gender, ethnicity and cultural background) and personal qualities (patience, compassion, sensitivity and empathy) as important in receiving positive care (Innes et al 2006). Older people also reported they expect the following in care delivery: valued and treated with respect, treated as a person, having a say in services, receiving value for money, a good fit with existing care giving/receiving within the family and a good fit with cultural and religious preferences (Qureshi et al 1999). Although, making decisions is reported to be an unpredictable process.

Decision making is not a linear process (Brown 2011). It is not a systematic, step by step process that can be calculated. Research suggests emotions strongly influence decision making (Brown 2011; Sanfey et al 2003). Most decisions also have a status quo alternative-to make no action or maintain the current/previous decision. One example illustrated a status quo bias in decisions on choices in choosing retirement and health plans (Samuelson & Zeckhauser 1988). The review also revealed what is important to older people.

The things revealed to be important to older people included choice (Craig 2004; Glynn et al 2008; Ware et al 2003), control (Bowers et al 2009; Craig 2004), independence (Bell et al 2006) and QoL (Fernandez-Ballesteros 2011).

Choice

Choice (Glynn et al 2008; Ware et al 2003) was important and overlapped into all key areas. Some programs support choice such as, 'Self-directed support (SDS) allows people needing social care services to exercise greater choice and control over how they receive services and support' (Rummery et al 2012, p.1). Individuals have charge of their SDS budgets (or individuals give control back to the council) to meet prior agreed outcomes of the individual, which demonstrate the opportunity for informed choices and opportunity of individual control in care options (Scottish Government 2010). This opportunity of choice and control demonstrates other influences, including: 'inclusion, dignity, and equality… with core values of respect, fairness, independence, freedom and safety' (Scottish Government 2010, p. 7-8). These things are consistent with what is valued and important to older people, support choice and meet some basic needs although this program is reportedly not utilised by all people eligible.

Options related to available choice involve influencing factors such as: the range of services available, opportunities through informal care and support networks, and other formal care resources or privately paying for care so people can get the exact services they want. Sometimes there is only one option; yet people still want to be consulted about what they think. For example, Ware et al (2003) reviewed care choices offered to older people in residential and nursing care services and found sometimes no choices were offered, limited choices of only staying at home or

moving into residential care were the only options offered, and in some cases-care decisions occurred without consulting older people or carers.

The literature also suggests no choice is offered (Bland 1999; Phillips 2007; Ware et al 2003). Some reasons for limited choices may include the lack of service availability, cost and speed of receiving appropriate funding to cover the cost of services (Ware et al 2003). People getting their care needs met through informal care or other service providers are sometimes restricted access to formal care (Vestri 2007). There are multiple reasons why choice could be restricted or not offered, affecting decisions.

When it came to choice of formal services, the services that people need and the areas where services are offered are sometimes two different things (Clough et al 2007; Ware et al 2003). Research does not provide evidence that services people want are the services they receive. Age UK (n.d.) reports 'However, people may find there is no choice of local services to buy with their direct payments' (p. 16). Carers and older people's wishes are to receive help in the areas of needed services (Leadbeater & Lownsbrough 2005). Other reported barriers to services include lack of information, inflexibility of services that do not change due to traditions, lack of money and resources, policy variation on paying for services and lack of communication (Glynn et al 2008).

Limitations of social care services extend to both older people and informal carers involved in service utilisation. Carers were concerned about the lack of choice and personal input into care plans for services (Vestri 2007). Older people and carers both stated concerns that people should be able to try services without being locked into processes that are difficult to change (Leadbeater & Lownsbrough 2005). There is a lack of information reported to allow people to make informed choices on contracting services (Bowers et al 2009; Vestri 2007; Ware et al 2003). Older people expressed having little choice in choosing care services, being uneducated in options available, and insufficient information on services to make informed choices (Ware et al 2003). Having opportunities and options empower people to employ control and independence.

Control and Independence

Control (Bowers et al 2009; Craig 2004) and independence (Bell et al 2006) to uphold dignity are important to older people (Craig 2004). Bowers et al (2009) refers to control as, "focusing on those aspects that promote independent living" (p. 11). This can be evidenced by individual choice of services available (Innes et al 2006). For example, Siding and Aronson (2003) report ways social ties shrink over time with increased social isolation affecting older people, citing an example of a participant utilising support to hire someone to come in and do laundry and watch television with her for her evening activity. This is personalised service which promotes independent living through control. It includes personal autonomy (Bowers et al 2009) and independence to remain in her home. This situation could promote social interaction and feeling part of the community by keeping current on outside events through care staff interactions. The participant also maintains dignity (Craig 2004) and increased self-esteem (Bowers et al 2009) by receiving assistance with personalized support she cannot complete herself.

Sometimes people pay privately out of their own finances for care services that are free, particularly in Scottish Local Authority (LA) systems (Bell 2010). Some reasons older people do not utilize eligible services include prior negative experiences with quality of services, stigma labels (such as disabled, gender or class influences), limitations of services to meet needs, facade of self-reliance, and fear of being a burden to friends and family members (Cordingly et al 2001). One example of this was an older woman reluctant to invite others into her house as she viewed her home as dirty due to lack of cleaning support services (unable to complete tasks herself) and stigma in getting housekeeping assistance that clashed with her gender/class beliefs (Cordingly et al 2001). In contrast, Clough et al (2007) reports, 'Many older people have a practical attitude towards help (as opposed to direct care) and will accept what is available when they need it' (p. 69). The literature also reported sometimes choice was only an option in situations when personal resources were used to fund services (Bowers et al 2009). These contrasting views indicate multiple sides of the issue, supporting the complexities of the issues involved, and merit additional research. Decisions can also be controlled by professionals deciding to offer choice or not dependent on how they view situations, and strongly influences individual situations.

At times, it was reported older people in specific circumstances were not capable of undertaking more direct control of care choices. Bowers et al (2009) reported people wanted more direct control of care and in some cases may be unable

to undertake additional responsibilities without the assistance of additional supports. However, in most situations as previous discussion revealed, specific reasons for professionals not allowing older people any choice, did not involve the inability of individuals to undertake control of their care. Bowers et al (2009) reported that staff at times thought older people, 'they would really not be interested… are too tired…it is too taxing for them' when in fact it was found to be the opposite when older people were directly asked (p.32). A variety of reasons offered for the lack of choice and opportunity in care decision making was reported.

Although it is reported that choice is not being offered to older persons due to those perceived persons limitations to undertake additional control in care choices (such as in direct payment situations), it is suggested that staff and professionals move from the mind set of 'looking after' or 'caring for' people that have higher care needs to roles that promote more 'inclusion... and citizenship' (Bowers et al 2009 p. 32). This has resulted in some cases such as self-directed support to implement additional supports and resources for older people and caregivers to support care choices (Scottish Government, nd). Professionals' motivations for offering (or not offering) client choices may vary per individual. However, with the influence of additional resources this allows the chance of added opportunity for personal involvement in the decision making process for care choices by older people.

There is confusion when an older person has the right to make a bad decision and when they do not. Brown (2011) discusses the role of capacity and professional's responsibility when people are entitled to make unwise decisions. These unwise decisions are allowable under the law (when people have capacity), as long as the decision is made in reference to all the facts, often causing controversy that requires judgement in the legal court system (Brown 2011). Older people have the right to make decisions for themselves, although the opportunities may not always be offered to them. It is reported people want to remain at home for as long as possible, this may cause issue in specific situations if at risk of physically falling or near the end of life. It is personal perceptions that also influence QoL, both from the older person's perspective and professionals.

Quality of Life

The World Health Organization Quality of Life (WHOQOL) Group (1995) define QoL as, 'individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns' (p. 1405). Older people want to remain at home for as long as possible, and when they do receive care they want it to accommodate their needs. Older people want home and personal surroundings (Bowers et al 2009) and prefer to receive dignified care and support at home, which is flexible and personal to their needs (Centre for Policy on Ageing 2011). The UK policy approach to long term care is to preserve individuals' independence, enabling them to live at home for as long as possible (Phillips 2007). However, QoL is multi-dimensional (Fernandez-Ballesteros 2011) and is not limited exclusively to where people live but influences many areas of people's lives such as their values, culture, social connections, and meaningful daily and community life.

QoL is affected by meaningful daily and community life (Bowers et al 2009) seen in both support and the lack of support. For example, human behaviour is purposeful in fulfilling basic needs (Glasser 1975; Howatt 2001). People had a holistic perspective when personal needs were assessed to raise QoL to acceptable levels which included: meeting of basic physical needs, personal safety and security, being able to live in a clean and tidy environment, keeping alert and active, access to social contact and company and being in control of your life (Qureshi et al 1999). The holistic principle of QoL is a key consideration in decision making processes in both what is important to people and how they make decisions.

How do Older People Make Decisions about Care, Support and Resource Utilization?

Decision making can be made on an individual level (Samuelson & Zeckhauser 1998; Sanfey et al 2003) or be collective, shared decision-making (Bowes et al 1997; Charles et al 1997) as an interactive process with several people (Bowes et al 1997) or on a societal level (Sanfey et al 2003). Bowes et al (1997) reports examples of decisions made mutually between husband and wife, by the head of the household or influenced by other household members.

Family and personal connections, resources and personal values all influence older people remaining in the home for as long as possible; although, older people do

not want to become a burden to friends and family members (Cordingly et al 2001). However, older people prefer to stay in their own home and community care is one example of support allowing that to happen (Bernabei et al 1998; Ware et al 2003) complementing informal care and may reduce stress on informal carers. Older people have voiced the opinion they value the help they receive promoting health, wellbeing and QoL through practical supports allowing them to continue living in their own homes (Centre for Policy on Ageing 2011).

In the context of increasing longevity, it is essential that research is critical of perspectives that construct older people negatively, and starts to contribute to understanding positive ways in which older people can influence their own choices about their care and support. Some researchers have started to identify ways in which existing care services can breach older people's human rights as they fail to acknowledge them as contributing citizens which undermines self-determination (Kelly & Innes 2012). Researchers report when home care is needed as QoL decreases in end of life situations; this may increase feelings of failure as an independent citizen (Siding & Aronson 2003). There is a gap in the evidence base in how older people make decisions based on actual behaviours, particularly as they become more vulnerable. What is understood is that choice (and the lack of) is a central part of the decision making process of older people. Key findings revealed in the search for decision making included unmet need, meaningful relationships and informal care (Bowers et al 2009).

Unmet Needs

The services people need are not always the services they receive and sometimes they go without, due to no options. Similarly, people do not make decisions to meet all their needs, as would be expected. There are multiple reasons for unmet needs. Bell et al (2006) reveals a lack of service utilisation with unmet needs as there appears to be 'indirect evidence that certain groups do not seek service support despite need…' (p. 2). Glynn et al (2008) reveals that service recipients are worried about LA charges, and this can stop people from asking for services and encourages people to ask for less as a result of paying for care. Similar findings (Reid 2009) in health care revealed when payment was required for services it deterred

individuals from seeking care which decreased service utilization rates (Couffinhal & Paris 2001; Reid 2009).

People often lack choice and can be excluded from services. Bell et al (2006) reveals a lack of service utilisation with unmet needs as there appears to be 'indirect evidence that certain groups … face exclusionary processes which means their needs are not met' (p. 2). One example, where people live can determine if they qualify for services or not, depending on how the LA interprets policy in Scotland. There are variations and expenditure differences between LAs in Scotland (Bell et al 2007; Bell et al 2006) as services that are covered in one LA can be excluded in others. Similarly, once people start receiving services they may develop unmet needs, as needs change over time. Both service recipients and carers stated they should be asked about needs with follow up inquires (Leadbeater & Lownsbrough 2005). Also, Ware et al (2003) reveals poor recording of unmet needs that could be used to modify services. Likewise, people find out about additional services in different ways.

People make decisions about care based on what friends and family tell them, the media and prior experiences. This may leave gaps in services and available resources, incorrect information could be relayed, and people do not always know where to go for answers. Social networking influences behaviours as older people are, 'ill-informed about services and benefits and often rely on family and friends for information' (Ware et al 2003, p. 417). Other reasons people decide on care (or not) is previous experience (Qureshi et al 1999) including prior negative experiences and stigma (Cordingly et al 2001). Media also affects decisions as older people had read about a care policy in the paper but were unsure if they qualified for services, and had confusion about which services were free and which services had fees (Audit Scotland 2008). Difficulties and confusion are not just experienced by older people but also extend to carers.

Older people and their carers are reluctant to express opinions when things go wrong, and have difficulties expressing concerns or complaints (Ware et al 2003). For instance, service recipients and carers were confused about roles and professional boundaries as, '"No one explains who is doing what and why: it is assumed people understand"' (Leadbeater & Lownsbrough 2005, p. 24). In another case, some comments included, '"you get fed up of fighting…I don't want to get anybody in trouble…I accept what I am given…don't want to make a fuss"' (Ware et al 2003, p.

13

419). Service recipients feel they are not being heard, and reported that staff think they know what service recipients need (Bowers et al 2009; Glynn et al 2008).

It was reported older people seem to lack of follow through on filing complaints if services or staff does not meet expectations such as missed or delayed visits, staff attitudes and tasks not getting completed, '…[new workers should] shadow existing workers to learn the ropes. Users had to explain how to do things… mentioned problems with attitudes of paid carers' (Ware et al 2003, p. 418). Sinding and Aronson (2003) report that people receiving end-of-life care were committed to 'making do' and also refraining from complaints. A service recipient stated, 'I wouldn't tell anyone if I was depressed-just get on with it-which happens quite a lot' (Bowers et al 2009, p. 32). Additional research is warranted as older people and carers appear reluctant to complain, which could relate to many areas including relationships.

Meaningful Relationships

Decision making appears to be influenced by meaningful relationships (Bowers et al 2009). Older people and carers both stated the relationship with the individual professional was most important (Vestri 2007). Ware et al (2003) revealed the establishment of long-term personal relationships and continued continuity of care is important to older people. The preference of long-term relationships leads to better working relationships, and a desire to see more time allocated to match staff with individual's care needs (Leadbeater & Lownsbrough 2005). Relationships between older people, managers and staff was reported as important (Bowers et al 2009; Glynn et al 2008). A well-developed relationship is reciprocal to professionals, informal carers and older people and may influence care decisions.

Environmental factors may influence older people's decisions. Relationships of those involved with care can be complex, and often informal care is used in addition to formal care to meet older people's needs. Nolan et al (2003) reports the complexities in relationships between informal caregivers, older people and formal caregivers and discussed barriers and approaches to building effective partnerships. Some barriers were previously mentioned when older people were reluctant to complain and could also be applicable here. Ware et al (2003) reports the importance of building relationships so, 'older people can be treated as active whole people, not

14

simply as passive service recipients' (p. 426). Service collaboration with transparent relationships could be more effective to meet needs.

Family dynamics can be complex when family is involved in providing care, creating complex relationships with possible changes in family roles (Nolan et al 2003). For example, when an adult daughter/son provides care to an aging parent, the daughter/son takes on more of a maternal or paternal role that their parent previously held. The reasons people provide care are also complex, and they decide to provide care for many reasons with multiple motivators. There are many family changes that affect intergenerational relationships and care such as divorce, step families, same gender couples (and LGBTQ households) that all affect the changing of traditional beliefs of duty and obligation (Phillips 2007). This could be seen differently from the view of the carer versus the view of the older person based on values, lifespan and other factors. These factors can be intricate and additional research is warranted to explore the significance of how relationships affect decisions about care and resources.

Care recipients have stated they do not wish to impose on family and friends, but value the care, support and other people's time in caregiving that allows them control in life and to get out and about to stay physically active (Katz et al 2011). Informal care can allow older people with disability or illness to remain in their own homes as a result of the care provided to them (Nolan et al 2003). Without the established relationships there would be no possibility for informal care and support received. Relationships influence the opportunity and choices available in decisions and the role that informal care allows older people.

Informal Care

Older people influence decisions about other people's care by offering informal care (can be given to people who are of a similar age). Informal care is care given with no fees involved typically by a spouse, family member or friend. This usually allows additional options and choice in decision making by allowing people control over how their needs may be taken care of or not. Leontaridi and Bell (2002) determined 7.5 percent of the adult's in Scotland were involved with informal care for people age 65 or older with the largest group being retired people providing care in the home setting.

Older people's views and preferences on people caring for them depended on a person's gender, race or ethnicity (Cordingly et al 2001). For example, one woman living with her two brothers reported, "I don't want to be in bed and an invalid. I wouldn't like my brothers to look after me. You need a woman" (Cordingly et al 2001, p. 10). Many older people offer care to others and receive care. Informal care is one of many ways support is received.

There are opportunities to remain in the home for as long as possible without becoming a burden, if some ongoing supports are known about and utilised prior to becoming stressed or carers become burned out (Age UK n.d.). Paid care opportunities such as respite care for caregivers (Nolan et al 2003) allows a break for informal or family carers. For example, programs such as the adult day care can also be a form of respite for a short time or also an ongoing support while an informal carer maintains a full-time job. This can often be the case if a family carer is an adult son or daughter taking care of aging parent and needs daily care while attending employment, then the adult son or daughter are able to attend to caregiving of the aging parent in the evenings, overnights and weekends. Other options to be found is a carer benefit and also carer support groups (Age UK n.d.). These supports can allow older people and carers additional options and opportunities in influencing care and support.

Conclusion

Exploration utilising the grounded theory approach revealed choice was important to older people and influenced decision making about care, support and resource utilisation. Older people prefer being asked their preferences on options and care decisions and being actively involved in the decision making process; this was evidenced by being informed and educated about options and resources, although this was reported to not always occur. Having a say was preferred even when only one choice was available, taking the time to communicate and build relationships was the preference.

Older people wanted to stay in the home setting for as long as possible, without becoming a burden. There are many supports and programs available to older people to supplement informal care such as SDS supporting choice to make staying in the home possible without becoming a burden if people know about them. Additional

care options are available for older people and carers to reduce stress and burnout such as adult daycare for respite care, offering choices for both the older person and carer. Where people decided to live had influences on many other areas in life, and QoL was found to be multidimensional with implications in most key findings along with choice. This related to overall control and independence which were found to be very important to older people to promote independent living.

The way older people decide on specific care derived from previous experience, family and friend recommendations and media. Relationships and informal care networks also influenced decision making which has implications on the structures and the types of decision making utilised such as family decision making models or shared decision making. Those involved also voiced they preferred well established, long term relationships in both formal and informal care settings. The review also revealed that sometimes older people and carers were reluctant to complain in examples when care had already been established further affecting the outcomes of decision making processes. This suggests meaningful relationships had multiple influencing factors on decisions.

Whilst some preferences are known, and decision making, choice and QoL are key considerations in these, how the process of negotiating care occurs, how people make choices - although often constrained choices - how they expend or conserve their resources, including their financial resources, remains poorly understood. Additional inquiry is needed particularly for older people with higher care needs based on actual behaviours and preferences. Additional research is also needed that portrays older people with daily care needs in positive roles as active participants in care decisions.

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Appendix A
Review Process and Search Terms

Topic: Views				
Databases	**Search Terms**	**Specifications**	**Results**	**Total Kept**
ProQuest	Older people or aged or geriatrics; and opinion or view; and care services or social care	Timeframe= limited & last three years to narrow the search and also did an unlimited or non-restricted time	19,128	(n =3)
Web of Knowledge	Older people or elderly or aged or geriatrics; and view or opinion; and care services or social care	1997 onward	10,000	(n =4)
Joseph Rowntree Foundation	None, scanned through listed research	None	N/A	(n= 1)
*Other	N/A	N/A	N/A	(n=15)
Grand Total				23

*A very helpful reference librarian supplied me applicable research and I am unaware of her search terms for the articles used and referenced in this work. Previous research was reviewed on the topic from the initial inquiry and from previous work. References were also taken from bibliographies and reference lists of articles.

Topic: QoL				
Databases	**Search Terms**	**Specifications**	**Results**	**Total Kept**
Social Care Online	Quality of life; care, older people and quality of life; "quality of life" and care" and "older people or elderly or geriatric" none	None	1389	(n= 0)
Social Services Knowledge Scotland	Quality of life and care;	Articles only: 3, search within journals: Journal "Applied Research in QL"; Applied Research in Quality of Life Volume 1 / 2006 - Volume 6 / 2011; Health and Quality of Life Outcomes journal	180, 100	(n= 4)
	Quality of life and care; Quality of life and care and older adults	2010 and 2011	808, 287, 36	(n= 1)
Web of Knowledge	Quality of life and care; older adults, geriatrics	2010, UK, Europe or Scotland	93,592, 7197, 375, 2	(n= 0)

Google Scholar	"quality of life" and "care" and elderly, aged, older people or geriatrics; "quality of life" and "care", relationships and elderly, aged, older people or geriatrics;		16,200	
		UK or Scotland	1,990	
	"quality of life" and relationship with "care", relationships and elderly, aged, older people or geriatrics;	UK or Scotland	1,170	
	"quality of life" and relationship with "care," relationships and elderly, aged, older people or geriatrics;	UK or Scotland	1,080	
	relationship between "quality of life and care" UK or Scotland, and elderly, aged, older people or geriatrics; Measuring "quality of life and care" and elderly, aged, older people or geriatrics	UK or Scotland	11	(n= 1)
				(n= 9)
Sociological Abstracts	"quality of life" and "care" and elderly, aged, older people or geriatrics;		368	
		2011	45	
	relationship between "quality of life" AND "care" AND elderly, aged, older people OR geriatrics);	2011	1598	
	relationship between "quality of life" AND "care" AND elderly, aged, older people OR geriatrics;	2011 and UK	6652	
	"relationship between quality of life and care" AND elderly, aged, older people OR geriatrics;	2011 and UK	6649	
	"relationship between quality of life and care" AND elderly, aged, older people OR geriatrics;	UK or Scotland	6255	
	quality of life measures		44926	
	Quality of life measures or assessments and aging, older adults or geriatrics;		8605	
	Quality of life measures or assessments and		2691	

	aging, older adults or geriatrics and UK; Quality of life measures or assessments and aging, older adults or geriatrics and UK and relationships between care and quality of life;		2203	
	defining Quality of life" and aging, older adults or geriatrics and UK; defining Quality of life, relationships and care" and aging, older adults or geriatrics and UK		519	(n=6)
Joseph Rowntree Foundation	Quality of life and care, visual search	None	N/A	(n= 2)
*Other	N/A	N/A	N/A	(n=11)
Grand Total				**34**

Topic: Informal Care				
Databases	**Search Terms**	**Specifications**	**Results**	**Total Kept**
ASSIA	Intersectionality, care and older people; intersectionality;		72	
	intersectionality and older people; intersectionality and care		6	
	all (unpaid care) OR (family care) AND (older people); ("unpaid care") OR (family care) AND (older people) AND (Scotland)	Scotland	2200 43	(n=5)
Searched online	Scottish government statistics and informal care	Looked for specific characteristics and demographics in Scotland	(massive search results)	(n=4)
*Other	N/A	N/A	N/A	(n=21)
Grand Total				**30**

Topic: Formal Care				
Databases	**Search Terms**	**Specifications**	**Results**	**Total Kept**
Joseph Rowntree Foundation	Formal Care, Long Term Care, Free Personal Care, visual search			(n=7)
Searched online	Government statistics, policy, legislation and reports			(n=15)
*Other	N/A	N/A	N/A	(n=5)
Updated Search- Collective Journals, online search of statistics…	Formal Care, Paid Care, Long Term Care, Personal Care, Free Personal Care, Free Personal Care in Scotland, Free Personal Care in England,	UK or Scotland	**no new relevant data**	
Grand Total				**27**

Topic	Total Records
Views	23
QoL	34
Informal Care	30
Formal Care	27
Grand Total	114