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Article Title Page

Mapping the information-coping trajectory of young people with long term illness: An evidence based approach

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Structured Abstract:

Purpose We explore the relationship between information and coping from the experiences of young people coping with long term illness.
Methodology Situational Analysis was used as a methodological approach. It has roots in the Chicago Symbolic Interactionism School. Cartographic approaches enabled the analysis, mapping the complexities emerging from the data.
Findings
As the young people became more informed about their health conditions, and gained knowledge and understanding both about their illnesses, their own bodies and boundaries, their confidence and capacity to cope increased. Gaining confidence, the young people often wanted to share their knowledge becoming information providers themselves. From the data we identified five positions on an information-coping trajectory (1) Information deficiency (2) Feeling ill-informed (3) Needing an injection of information (4) Having information health and (5) Becoming an information donor.
Research limitations/implications The research was limited to an analysis of thirty narratives. The research contributes to information theory by mapping clearly the relationship between information and coping.

Practical and social implications The study establishes a relationship between levels of information and knowledge and the ability to cope with illness.

Originality/value The information theories in this study have originality and multi-disciplinary value in the management of health and illness, and information studies.

Keywords: information, coping, trajectory, Situational Analysis, young people, health information, information behaviour

Article Classification: Research paper

For internal production use only

Running Heads:

Introduction

This paper presents the findings of a study that re-uses (with permission) thirty interviews gathered by the charity DIPEx (Youthhealthtalk) to explore the relationship between information and coping where young people are coping with long-term illnesses. The study uses the analytical approach Situational Analysis, an elaboration of Grounded Theory developed by Clarke (2005). As the approach is not widely used in Library and Information Science research and will therefore be explained, before illustrating its application in this research context. The findings allow for the relationship between information and coping to be mapped presenting a model of the information-coping trajectory grounded in evidence, and drawing on previous studies.

The originality of this paper is that it uses the mapping techniques within situational analysis which have not been used previously in this context to map the relationship between information-coping based on evidence supplied by young people from their own experiences. Trajectory has been used in relation to illness; trajectory has been used in coping, but the information-coping trajectory has not been mapped explicitly and clearly in previous studies.

Background literature

Problems have been identified in supporting young people with information in healthcare contexts, with claims that health professionals have a "routine" approach to information support not necessarily meeting the needs of teenagers and young adults (Lewis et al., 2010). The period of transition from teenage years to adulthood is "known to be a particularly challenging time for young people generally" (Department of Health, 2006). Support and understanding is needed in helping the young person develop confidence in managing health conditions. Information is one form of social support that can help young people at this time of need. Decker et al (2004) identify the need to assess adolescents' information needs throughout the course of their treatment in order that healthcare professionals can develop meaningful interventions and help the young people cope. Thorne et al., (2004) identify the criticality of communicating information effectively and appropriately to help people cope with illness, with sensitivity needed in health communications (Buckloh et al., 2008).

There are a number of models, theories and discussions of communication on the complexity of information communication as a form of social support (Brashers, Neidig & Goldsmith, 2004; Folkman & Lazarus, 1988). Goldsmith and Fitch (1997: 454) present a situational study of communicating social support identifying complexity through potential contradictions or "dilemmas" where for example advice and support may be viewed by the receiver as either "helpful", a positive experience, or "butting in", a negative one. Lewis et al., (2010) present a theoretical framework to explain information exchange in the healthcare context specifically with young people. The model identifies both positive and negative influences of Information and knowledge exchange in clinical contexts during the transition years, aged 13-19. Recommendations are made to better support young people with their information needs such as building rapport in the clinical encounter, providing opportunities to talk without parents present, and giving more practical information.

Young, et al. (2003) show that young people's maturity, and their preferences for communication are not straightforward again showing contradictions, tensions, and in some cases binary oppositions e.g. doctor as hero/doctor as villain (Jakobson, 1971; Lèvi-Strauss, 1994, Saussure, 1983). These contradictions illustrate human individuality "everybody's different" and yet similarities, "everybody's

the same" (Verma, 1989) illustrating communication complexity, and requiring skillful handling, and understanding of the context. Contradictions also occur when individuals have different constructions of the situation or phenomenon i.e. having different understandings or perceptions (Strauss et al., 1981). These contradictions are noted in the coping literature by Folkman and Lazarus (1985) who studied emotion and coping within young people. Folkman and Lazarus's (1985) study identified three major themes: (1) the stressful encounter is dynamic and unfolding (2) people experience contradictory states of minds and emotions, (3) people cope in complex ways.

Trust is an important factor in health information; trust of the quality and authority of information itself, and trust of the authority of the communicator (Kefford et al., 2005; Rycroft-Malone et al., 2004). Building a rapport and trust with the healthcare professional who is often the information provider is often neglected (Young, et al., 2003), with young people feeling marginalized in health consultations. Work exploring the social positioning of children and young people and health care also reflects on that marginalization and the problems encountered (James and Prout 1990; Mayall, 1996).

Kefford et al., (2005) reinforce the need for not just trustworthy but accessible information for young people. There is a wider role than that of health providers, with the whole community having a role in the dissemination of health and lifestyle information through organisations such as youth groups, schools, and churches, friends and family. Kefford et al. (2005) also identified a desire within young people for a whole lifestyle approach to health, and therefore it is not surprising to find that young people exploit a range of information sources accessed in different ways including using technology to fulfill their information needs (Skinner et al., 2003; Franck et al., 2008; Ekberg et al., 2010).

Information behaviour has been studied for over fifty years, and there are numerous information behaviour models that could be applied in this context (Bawden and Robinson, 2012; Fisher, Erdelez, and McKechnie, 2005: Case, 2012). Some models are *descriptive* of the activities undertaken (Ellis, 1989), others outline the *process* considering the order of information behaviour (Wilson, 1999), whilst other models are non-linear aiming to capture the complexity of real world situations (Foster, 2004), and are categorised by Bawden and Robinson (2012) as *cognitive* models of information behaviour.

Young people experience a range of emotions when living with ill health that can be barriers to effective communication and coping; feelings of confusion, fear, and uncertainty (Decker, et al., 2007). Neville (1998) found that communicating information about illness as a form of social support can reduce uncertainty, and help people cope. Brashers and Jackson's (1997) work on communication identifies the importance of understanding the management of uncertainty in a health context where in some instances, people want to reduce uncertainty because it is threatening and at other times, uncertainty allows people to have hope and remain optimistic. Case et al (2005: 535) comment that "it has also long been noted that people may *avoid* information, if paying attention to it will cause mental discomfort or dissonance." Coping, avoidance, and stress are also addressed in information behaviour theory and Miller's (1980) "monitoring and blunting" theory positing that people have different information behaviours when coping with stressful situations, some choosing to monitor the situation as "knowing" helps to decrease stress, whilst others, "blunters" chose to avoid information as it increases their stress levels.

Frydenberg (2008: 21) observes that *"Stress and coping are arguably the most widely researched area of psychology"*, therefore any in depth discussion of such a breadth of research literature would be beyond the scope of this paper, especially as the discussion we present here is multi-disciplinary involving information behaviour, psychology, communications, and health sociology. However, coping is about

the way people manage often stressful life conditions (Lazarus, 2006). Key components of stress theory involve the individual appraising the significance of a situation, and managing the demands on them by coping (Lazarus and Folkman, 1984). Folkman & Lazarus (1988) have carried out extensive research and have identified eight key ways of coping: (1) confrontive coping, (2) distancing, (3) self controlling, (4) seeking social support, (5) accepting responsibility, (6) escape-avoidance, (7) planful problem solving, (8) positive re-appraisal; that people adopt in different situations. The communication of information is a form of social support, and can come from a number of information providers, formal such as health professionals, and informal such as friends and family. There is a need for health information by adolescent patients, those needs varying over time and at different stages of illness (Decker, et al., 2004; Hummelinck and Pollock, 2006). This information is critical in supporting healthcare decision making (Hokkanen, et al., 2004).

Coping can be described as a process (Lazarus, 2000; Parker and Endler, 1992), "…a function of continuous appraisal and reappraisals…". (Lazarus and Folkman, 1984: 142). The process of coping is a precursor to psychological growth and lessening anxiety (Shontz, 1975). This process is often related to coping associated with grieving and a sense of loss where individuals go through a number of stages, defined by Kübler-Ross (1969) as (1) denial, (2) anger, (3) bargaining, (4) depression, and (5) acceptance. Other researchers have identified their own staged models of coping in different situations (Table 1). Yet (Wortman, 2007: 2692) others dispute that coping does occur in a staged approach; *"Not everyone goes through an orderly sequence of reactions with defined stages."*, and argue that a person's ability to cope fluctuates. Nevertheless, the stages or fluctuations reflect the dynamic nature of coping, and this dynamism is represented in the nursing literature by what are called coping trajectories that consider the ability to cope alongside the progression of an illness (Garcia, 2010; Henly, Wyman and Findorff, 2011; Seiffe-Krenke, and Beyers, 2005). The concept of trajectory or the progression of an illness was initially developed from Grounded Theory by Glaser and Strauss (1965, 1968) and developed further by Corbin and Strauss (1991). It is used widely in research that combines health and social science issues and particularly by Brashers (1988, 2002) in studies of uncertainty and coping with HIV.

INSERT Table 1.

Frydenberg (2008:36) also discusses coping (specifically in relation to young people), describing it thus *"Coping represents thoughts feelings and actions that an individual uses to deal with problematic situations encountered in everyday life and in particular circumstances."* She identifies the coping process as having three key appraisal stages (Frydenberg, 2008). Primary appraisal is concerned with the individual's perceptions of the situation, the challenges, harm, threat and loss. The individual considers the situation and their potential coping interventions. Secondary appraisal takes into account the individual's characteristics, e.g. age, personality, temperament, hope and optimism. At this stage the young person draws on their interpersonal and personal resources. Their coping behaviour includes thoughts, feeling, and actions, and leads to outcomes, and tertiary appraisal, when a review of those outcomes occurs. These coping appraisal stages are set within a context of situational determinants, emotions, and what Frydenberg (2008:36) calls a "caravan of resources" – resources that you gather through life that can be taken with you - from work by Hobfoll et al. (2003). Support resources may come from, social support, social learning, and connectedness to family, friends, or school as support networks. If the environmental load substantially exceeds the person's resources then a stressful situation exists (Lazarus, 1988). These ideas are important to this study as they identify the importance of "resources" (information being one such resource) as support in the coping process, and acknowledge the complexity of the coping situation for young people.

Research objectives

This study explores the relationship between information and coping in the context of young people with long term health conditions. It analyses the situation holistically, and qualitatively examining the young persons' experiences within the social worlds they inhabit, what Clarke calls, *"the full situation of inquiry"* (Clarke, 2003: 556) seen through the lens of the young people. It draws on theories already discussed; coping, information as a resource and as a form of social support, information behaviour, and the idea of trajectory in the information-coping relationship. We consider information and knowledge exchanges, the young persons' social context, communication issues, relationships, and tensions experienced when learning to cope with their conditions. This goal was addressed by the following objectives:

1. Identify the information behaviour of young people affected by long term illness, expressed and evidenced by the young people themselves, relating to acquiring, communicating and sharing knowledge and information
2. To map such information behaviour onto contextual factors affecting the young people, in order to build a model of the role played by information and knowledge within the coping context.

Methodology

Methodological approach

Situational Analysis was selected as the approach adopted for this study as key researchers in stress and coping theory see the issues as situational (Folkman & Lazarus, 1988; Frydenberg, 2008; Lazarus and Folkman, 1984). Situational Analysis as an analytical approach was developed by Adele Clarke in the domains of the history of medicine and life sciences (Clarke, 2005), and has been used reasonably widely in a healthcare context, less so in information and communication studies (Vasconcelos, 2007). Situational Analysis is used as a "means of coherently elucidating and analyzing some of the complexities and instabilities of social life." (Clarke, 2003: 553) – making it appropriate for this study as coping with illness creates instabilities for those affected. It is a methodological approach with its roots in the Chicago Symbolic Interactionism School having a tradition of being used to explore social interactions in clinical contexts (Clarke and Montini, 1993; Clarke, 2005; Mills, Francis and Bonner, 2007).   The approach uses what it describes as "cartographic" approaches as a platform for analysis in mapping the complexities that emerge from the data (Clarke, 2003: 553). There are three main mapping techniques used to promote analytical thought and reflexivity in relation to the data (Clarke, 2005): (1) Situational maps that enable the initial study of the situation, considering the major human, non-human, discursive and other elements of concern, and the relationships amongst them; (2) Social worlds/arenas maps that allow the researcher to plot the actors, key non-human elements and the arena(s) of commitment within which they are engaged in their negotiations, and interpretations of the situation; (3) Positional maps developed to plot the major positions taken, and not taken taking note of discursive variations, difference, conflict and controversy surrounding the complexities of the situation. Together the maps focus on elucidating complexities, and are used analytically to question the data (Clarke, 2003: 561; Clarke, 2005).   The situation of inquiry is the unit of analysis. In this case the situation is coping with long term illness.

Situational Analysis lends itself to a variety of domains due to its flexibility in application (Bone, 2002; Vasconcelos, 2007; Vasconcelos, et al., 2012). Situational Analysis is an expansion of the Arena/Social Worlds framework which explores social worlds as different arenas where multiple worldviews exist

with processes of negotiated interaction (Strauss, et al., 1981; Clarke, 2005). Social worlds can vary in size, type, numbers, activities, organizational complexity, ideologies and geographical dispersion (Weiner, 1991). Social worlds are groups with shared commitments to activities (Clarke, 1991). They come together in arenas where they focus on a given issue, and are prepared to act in some way (Strauss et al. 1981).

The concepts of arenas and social worlds are therefore interlinked - 'Intrinsic to the sociological concept of arenas is the idea that they are composed of social worlds' (Wiener, 1991: 176). An example of different social worlds might be the social worlds of the young people who come to the health care arena to discuss their health care with health professionals who will exist within their own social worlds. Situational Analysis is a constructionist approach that acknowledges different constructions of phenomena will exist. The multiple perspectives will inevitably bring, within the communication exchanges or discourses, conflict, cooperation, and negotiation (Strauss et al. 1981). As the communication of information during coping is central to this study, this reinforces the appropriateness of Situation Analysis as an approach.

Situational Analysis seeks to identify differences, variations, conditionality, complexity, and silent voices. It can be used in a wide range of research projects using different data gathering approaches. This method may seem formulaic for a qualitative approach to data analysis, however it offers a systematic approach to "interrogating data analytically, demanding careful consideration and considerable reflexivity on the part of the researcher" (Clarke: 2005: 141). It involves constant reappraisal of the data (the situation) through the analytical process to get a sense of the issues of concern. The iterative process of appraising and re-appraising the data, combined with memoing, and reflective techniques supports deep interrogation of the data.

Data

Thirty patient stories are openly available online via the Youth Health Talk website from young people coping with long term illness s(http://www.youthhealthtalk.org). Other stories are available on the site but for this study we focused on long term conditions to give a longer term perspective of the young peoples' experiences, and how their use of information, and coping strategies changed over time. A wide range of health conditions can be categorized as "long term" which adds breadth to the study avoiding a narrow focus on one health problem.   We used all thirty available narratives in this study. The patient stories were gathered by the charity DIPEx for the Youthhealthtalk project founded in 2001 to enable patients to learn from others experiencing similar health problems. The website is a source of support for teenagers and young people with a wide range of health concerns. The stories had been video recorded, transcribed, and made available online. The project covers a range of health conditions (Ziebland and McPherson, 2006). Permission was given by DIPEx for us to use the stories. The young people were aged 16-29 years at the time of interview, though their illnesses had been diagnosed some years before. Their conditions include epilepsy, asthma, sickle cell anemia, cystic fibrosis, juvenile chronic arthritis, diabetes, chronic pelvic pain, and celiac disease.

Data analysis process

The data were open-coded and analyzed to reveal relationships between individual and collective actors within the situation, and to explore the major discursive issues. The analysis was conducted In accordance with the Situational Analysis approach. This involves diagrammatical or "cartographic" approaches to encourage a deep analysis of the data content (Outhwaite and Turner, 2007). Open

coding and memo writing is used in the initial stages of analysis. The mapping of the coded data is designed to provide insights into situational complexity. The method can also highlight "sites of silence" in the data, those things that are "unarticulated" - absent voices (Clarke, 2003: 561).

The first situational map identifies the major elements of concern in the research rather like a mind map. This initial map is exploratory in nature and aims to capture the messy complexity of the situation (Clarke, 2003: 539), and relationships between key human and non-human actors or actants; actants being anything that modifies other actors behaviour through a series of actions (Latour, 2004). The mapping is carried out using a questioning approach, used in conjunction with memoing and reflection. Key questions that might be asked during this process are: Who and what are in this situation? Who and what matters in this situation? What is going on in this situation? What elements make a difference in this situation? What ideas, concepts, ideologies, discussion, symbols, sites of debates, cultural issues, discussions, symbols matter in this situation? What seems present but is unarticulated?

The initial or "messy maps" may have many iterations to ensure that all the key issues have been identified (Figure 1). A relational analysis can be done at this stage by circling elements identified in the situational map, drawing lines between the elements and specifying and describing the nature of the relationships.

INSERT Figure 1.

The key concepts identified through a messy map are then ordered or categorised (usually in a table – Table 2) to help understand the relationships. It is useful to use both the "messy map" and the "ordered map" simultaneously to avoid overlooking important issues, and to consider relationships. For the ordered map Clarke (2005) supplies a number of headings to aid the analytical process (Table 1). The next main mapping exercise, the social worlds/arenas map lays out the collective actors and the arena(s) of commitment where negotiations take place (Figure 1). The maps are not necessarily produced within the findings; they are analytical mapping exercises for exploring the data. However, for purposes of illustration we have included example maps (Figure 1-3, Table 1). The focus of our study centres on two of the main maps, the maps the social worlds/arenas map, and the positional map to aid the illustration of our findings (Figures 2 and 3). Researchers do not have to use all the mapping techniques, but can draw on them rather like a toolkit to support analysis selecting those tools most appropriate for the task, though in this study we found all the tools and techniques valuable.

INSERT Table 2.

The next stage is positional mapping used to lay out positions taken identified from the data on major issues (Clarke: 2005: 126). Positional mapping is not as widely used as the other techniques. The output serves as a visualisation tool, and also promotes reflection and analysis. Our findings in relation to all the mapping techniques will be discussed in the following section alongside illustrative comments from the data.

Why situational maps? Why not any number of other qualitative techniques such as discourse analysis, content analysis, thematic analysis? Or other methodologies that adopt mapping techniques such as Information Horizons (Sonnenwald, 2005), and the rich pictures used by Checkland in Soft Systems Methodology (Checkland and Scholes, 1999). Information Horizons whilst it acknowledges the importance of situation and contexts, uses mapping techniques primarily as data collection tools with

the individuals carrying out the mapping. What we wanted with this study was a wider exploratory focus on a situation of enquiry. It could be argued that Checkland's rich pictures would perform this function, used in Soft System Methodology, as the focus here is on a situation and should encompass multiple perspectives. The rich picture aligns quite well to the Social worlds/arenas map in situational analysis. Where the mapping techniques in SA scores, is from the earlier mapping in the "messy" and ordered phases that allows for a more systematic approach to the data analysis stages, and in the final stage of positional mapping, that enables a key issue to be explored in greater depth, and allows for relationships to be plotted. As with any study, it is a matter of finding an approach that is appropriate and works in the specific context, and being able to justify those research decisions (Bryman, 2008).

The mapping techniques in SA encourage a systematic approach to data analysis, encourage iterative analytical techniques, and deep reflection when considering the data content and relationships in the data. Clarke (2005) praises the usefulness of the technique and of the visual representations that provoke thought, open up knowledge spaces, and enhance the opportunity of reflexivity. The approach is also an elaboration of Grounded Theory, and therefore aligns well to the concepts of trajectory previously discussed in relation to the progression of illness, and suited this particular situation.

Following the identification and modeling of the information trajectory the data was subjected to secondary coding using the information-coping trajectory model as a framework for that analysis.

Findings

This section discusses the key findings in relation to the two main illustrative maps used in this analysis; (1) the social/worlds arenas map that presents the overall situation of inquiry, the key actors and issues identified in the data; and (2) the positional map presenting the relationship between information and coping in this situation.

The situation of inquiry as illustrated in the social worlds/arenas map

The mapping techniques used were particularly useful in identifying the individual and collectives, their social worlds, arenas of interaction, and positions adopted on key issues within in the situation. Individuals or actors were identified, for example the young person, the doctor, the friend, mum. Key groups were identified e.g. friends, family, health professionals, support groups. The individuals and groups of individuals occupy different social worlds within what can be categorized as either personal or institutional worlds/arenas, with their own and often different constructions of phenomena e.g. health information (Figure 2).

Figure 2 illustrates that multiplicity of social support within the Social Worlds that the young people inhabit, both personal and institutional, that provide a support network for the young people, and provide arenas where information is accessed, knowledge is shared, and experiences gained.

INSERT Figure 2.

At the centre of this situation of inquiry are the young people, drawing on a "caravan of resources" (Hobfoll, 2003: 81) coping as individuals sometimes with support, sometimes forming coping groups or collectives by accessing support groups or virtual communities in online forums. Many studies have identified the benefits of patients attending support groups (Fudge and Mason, 2004; Coppa & Boyle, 2003; Olsson, 2005), and Chappie et al., (2004) suggest that not attending a support group can lead to

stigmatization. The young people in this study had mixed opinions on the usefulness of support groups, but did not identify stigmatization as an issue:

> *"Talking about it [the condition] can be boring… so that is why I don't go to a support group."* [Rollo, 23yrs]

> *"Yeah – just good to talk to other people about it [the condition] and to use the Kick Asthma holiday camps are really useful. I recommend it."* [David, 18yrs]

> *"Looking back – S***. Why didn't I go to any of these things? Why didn't I see a counselor about it? Why didn't I go to a support group?" Because probably if I'd done those things I would have understood it [the condition] better and probably not felt so unhappy about it"* [Lara, 18yrs].

Support groups were highlighted as information providers, often being accessed via the Internet. They were used when others, for example, health professionals and the NHS, failed.

> *" I was never advised to by my doctor or anything but I read a study on an arthritis website, I can't remember which one it was, but it was one of the major charities for it, and it said that they'd shown that taking cod liver oil regularly can prevent the disease from progressing…"* [Sara, 21yrs].

There is a need for young people to have both normative and health specific support (Barker et al., 2005). Failure to meet information needs could be construed as what Barker et al. (2005) term as social support being hindered, leaving people to find their own solutions. This can lead to exclusion for those who lack health literacy skills, and/or access to technology.

Kaplan et al., (1977) highlight a number of key variables in social support research including, the psycho-social needs of the person, relationships as sources of support, and characteristics of the environment, including types of stresses or social processes and structural characteristics which may inhibit or facilitate behaviours and relationships.

Relationships came through strongly as important socially interactive support mechanisms e.g. family networks, friends, and social institutions such as school, work or church. The young people spoke of the importance of *"letting friends know, letting church people know"* and *"needing the support of others"* [Rollo, 23yrs]. Being open in this way allows for support and understanding to take place…" [Sophie, 19yrs]. Some did express a reluctance to tell people right away because they didn't want it to be the *"main point"* about them [Sara, 21yrs]. It is important for the young people to feel accepted, to still fit in, and continue, "smoking", "drinking" [Sara, 21yrs], *"go clubbing"* [Helene, 23yrs] and not *"feel completely isolated"* [Joseph, 17yrs]. Yet also important was the sense of individualism - *"everyone's different"* [Donna, 18yrs], a need to be independent, and find their own ways of coping with the illness - *"I hate relying on other people…"* [David, 18yrs]. These findings are illustrative of contradictions that appeared in the data that can be seen in Figure 2. The young people had different experiences whilst coping with their illnesses, expressing different opinions, sometimes complete opposites or polarity of opinions across a range of issues such as their relationships with their healthcare providers, and how their friends treated them when they became aware of the health problems.

What is seen in the data is that social support is "multi-dimensional", health services, charities, personal contacts (Kaplan et al. 1977: 47), which requires integration, collaboration and strong integrative communication infrastructures for effective exploitation (Rycroft-Malone et al. (2004). New technologies such as social media and the Internet can support integration, but then the young people or their carers need strong communication skills and health literacy skills to exploit resources to the full (Rickwood et al., 2007; Burns and Rapee, 2006; Whalen et al., 2007).

A key person in the support network is mum or mother. Other family members, dad and siblings were rarely mentioned. Mum was the dominant figure in the narratives: *"I talk in depth to my mother about it…"* [Rollo, 23yrs]; *"I've always had my mum look after me and then encourage me…"* [Helene, 23yrs].

One particularly strong theme that emerged from the data analysis was that as the young people became more informed about their illnesses, acquired knowledge about the conditions, and gained experience of dealing with the illnesses, then they became more confident at coping with ill health. It is this relationship in the data that is the focus of the following discussion.

Information and coping – the information-coping trajectory as illustrated by positional mapping

The research identified a number of positions illustrative of the young persons' development along an information-coping trajectory. The information-coping trajectory is a symbiotic relationship between information and coping. The positions on the trajectory have been categorized using medical language i.e. information deficiency, ill-informed, information injection, information health, and information donor. Positional mapping (Figure 3) allowed for the identification and mapping of these positions. Examples of quotes from the young people in this study that illustrate the positions are given in Table 2 and the positions on the trajectory are discussed in turn later in this section.

INSERT Figure 3.

- **Position 1 –** Having **Information deficiency**. A person who does not have enough information to understand the situation. A young person at pre-diagnosis or at diagnosis, may be lacking information, and could be described as information deficient. Little or no information or understanding, combined with a possible lack of maturity leaves the young person unable to cope and experiencing shock.
- **Position 2 –** Feeling **ill-informed**. A person who has basic information but may not be able to use that information effectively, may not have the right information to help their needs, thereby not achieving full information health. A Young person in the early stages of illness being given basic information, but often lacking sufficient information and may feel ill-informed. This leaves the young person in a state of confusion, they may experience fear, misunderstanding, and react with anger, denial or rebellion. This state may be caused by a number of factors including mis-information, information disconnects in the communication process, information illiteracy.
- **Position 3 –**Having an **Information injection**. When a person realizes they have an information need, or someone else sees that the person has an information need, an injection of information might fulfill that need. A Young person learning to cope with illness, has an information need, they seek, filter and synthesise information to boost their information to the right levels, addressing the information deficiency, and attaining information health. If they can't do the injection themselves, they may need help from others. With this information, they

develop understanding. They start to use this information, combined with experience to find ways of coping and adjusting to their health situation.

- **Position 4 –** Having **information health**. When a person has the information they need. A young person who feels informed, has gained knowledge and understanding, and feels confident in using that information to make decisions may be described as having information health. They start to negotiate their health care as they build on their resources, combining the information with their experience, and becoming more knowledgeable about their illness and their ability to cope.
- **Position 5 –** Being an **Information donor.** When a person has information that they can share to bring others to information health. The person has an altruistic view, and feels confident that they can help others to information health by sharing information, knowledge and their experience, becoming information providers/donors.

The information-coping trajectory - Position 1

- **Information deficiency**. A person who does not have enough information to understand the situation.

Eleven you people reported experiencing information deficiencies: *" I wasn't ever offered counseling or anything like that.*" [Annette, 19yrs], particularly at diagnosis – "*I didn't really know much about it [diabetes] at the time [diagnosis]".* [Andrew, 24yrs].

Diagnosis was memorable for all the young people in the interviews, with descriptions of shock and disbelief experienced by young people and their parents. This relates to a number of the coping theories outlined in Table 1 (Shontz, 1975; Horwitz, 1976; Maciejewski, 2007;).

"I went to my local GP who wasn't there and I saw a locum instead and he said that it looked like arthritis which was a bit of a shock to my parents. I was young so I just thought oh I don't really know what that means." Sara 21yrs

"…then we got the bad news that I had Duchenne Muscular Dystrophy…my mother was in shock." [Hassan, 18yrs).

The early stages of illness and diagnosis are particularly critical times when emotions are high, and trust of health professions can be low. Diagnosis is a critical point for communication and information transfer. There is a key support role here not just from family especially "mum" giving parental support (Illes and Lowton, 2010), but also health professionals (Decker et al, 2007). Diagnosis is a key time for information provision by health professionals, yet parents often find this lacking (Hummelinck and Pollock, 2006). Strong emotions emerged through the narratives with the use of figurative language; shock and fear was felt at this point in the patient journey: *"…it was quite awful to hear…I wasn't expecting it…and that was quite a big thing for us to deal with…"* [Kate, 21yrs], *"It was a real shock when I was diagnosed."*[Catherine, 29yrs], *"..it's just earth...you know earth shattering. …It's like having the rug pulled underneath you, your whole world….It was just as scary as hell."* [Clint, 26yrs]

We see the prolific use of figurative language in the discourse. Gibbs et al., state (2002) that this is often used when people want to express ideas that for whatever reason are difficult to communicate. Phrases such as *"earth shattering"* "*scary as hell"* give vivid illustrations of the emotional turmoil faced by the young person at diagnosis and project emotional intensity. Metaphorically, hell and shattered earth are

both things from which there is no return which is illustrative of hopelessness and fear experienced at this stage. Strong negative emotions experienced at this stage by both the young person and parents are widely acknowledged in the literature together with the importance of information support stressed at this time (Canam, 1993; Pain, 1999; Nuutila and Salanterä, 2006). At this stage the young people are not coping; they are often fearful, angry.

Particularly important in giving bad news is how it is communicated, with young people wanting their doctors to be friendly and approachable (Jones, et al., 1997). Here there were different experiences but those experiences were frequently negative.

> *"…another doctor came in and he sort of blurted it [the diagnosis] out..."* [Kate, 21yrs].

There is much in the literature discussing the difficulties for health professionals who have the job of explaining sometimes complex information when the recipient may be in shock, and the doctor if more junior may be fearful of the task in hand (Buckman, 1984, Barnett, 2002). However, as Sastre, et al., (2011) observe, physicians must appreciate that patients have high levels of expectations for both empathy and information quality no matter how bad the news that is being communicated.

The young people also reported the lack of information made available to them at this time; *"I wasn't given much information at the time…"* [Sara, 21yrs].

With hindsight, they wanted that information to be provided.

> *"I know now that there was a lot of information that I should have received, but I didn't…. I think throughout I would have wanted more information and I would have wanted more opportunity to ask questions…..it was only when I met my current doctor, who provided me with more information, that I went on to a different treatment that, that really improved the epilepsy. So I would have really valued more information about what it was and about the medications…".* Catherine 29yrs

> *"But having information available ... positive and negative, I think reaches a person at the, you know, at the right time, can make a huge difference to them…".* Lynn 28yrs

The combination of the stress of the situation, the lack of maturity of young people, the complex communication issues, and general lack of information lead to a stage of the young people feeling ill-informed.

The information-coping trajectory - Position 2

- **Ill-informed**. A person who has basic information but may not be able to use that information effectively, may not have the right information to help their needs, thereby not achieving full information health

In the early stages of the illness the young people and their families had little or no information, and were often feeling frightened or confused. Twenty-two of the thirty young people said they had felt ill-informed at some stage.

"I had no real kind of understanding of what HIV or Aids was. I just knew if I got it I was going to die because that was the image that is kind of projected through the media. …I was very naïve. I was very young, very believing, and I was lacking confidence it was because I just didn't have all the knowledge. I wasn't worldly enough". Clint 26yrs

"Because when I was younger… I never heard of you know dialysis, renal failure, the first thing I thought of was, well I am going to die. You know because at that age you don't think about transplant and all those different things." Donna 18yrs

There was some evidence of information being withheld, or presented in a positive light which left people misinformed.

"Even when you access medical services or, you know you speak to medical professionals and you want to get the best advice, because you're at such a young age sometimes they want to protect you, they don't want to just give you the information and that was what happened to me". Clint 26yrs

"…they, the doctors, said to me don't worry you have ten years of good health. But I didn't realise that when you actually do the research on the studies, 3% of people will develop Aids very rapidly". Clint 26yrs

Misinformation was reported elsewhere in the literature (Buckloh et al. 2008). Buckloh et al. (2008) also reported on the negative impact that a lack of information or withholding information can have leading to misunderstanding about the illness and possible maladjustment. A number of the young people reported that the lack of information and support had a negative impact on their health and wellbeing, and the ability to cope with their condition:

> *"I was never offered counseling…it definitely sent me into massive depression and I lost loads of confidence…I was really unhappy and felt like my whole life had been taken away from me.* [Annette, 19yrs]

Misunderstandings occurred on occasions due to poor communication:

> *"Cause sometimes doctors use all the medical terms and terminology and sometimes even the parents don't know what they're talking about. So it's like use words that are every day".* [James, 21yrs].

> *"They [doctors] have explained it the illness] to a certain extent but they haven't gone into any great detail….I've got questions that need answers and they haven't answered them… I haven't asked… Because I feel stupid."* [Sarah, 29yrs]

Others had much more positive experiences. Whatever the experiences, positive or negative this was a stage when the young people experienced feelings of confusion, anger, denial, and uncertainty *" I was really guilty of denying a lot of things and trying to pretend it wasn't happening."* [Miriam, 19yrs]. These negative emotions and reactions are identified as classic responses in the coping process (Kübler-Ross, 1969; Shontz, 1975; Horowitz, 1976).

The feelings of confusion, uncertainty, and often lack of information left the young people having to find sources of support and information. As we saw earlier, the information, and support comes of multiple

sources, for example, family, friends, health professionals, and support groups, yet many went to the Internet to fill the gap in their information needs to get an "injection" of information.

The information-coping trajectory - Position 3

- **Information injection**. When a person realizes they have an information need, or someone else sees that the person has an information need, then an injection of information might fulfill that need.

The majority (25) of young people reported having explicit information needs. The first place the young people looked to for information support was from the health professionals;
[Sources of information] "At first it was the hospital obviously. They advised us what the condition involved [Joseph 17yrs]. The experiences of the young people were both positive and negative.

The negative issues that were identified by the young people in this study were not dissimilar to other findings in the literature (Barnett, 2002). They including being talked down to, using an inappropriate level of language and medical terminology, not giving enough time, and a lack of sensitivity:

> *" I was 14 years old when, when it all started and I was you know going through pain, …I needed reassurance,…and I was talked down to and told I needed psychological help. ..It makes a huge difference, I mean, how that is communicated to a person. And I am not saying that you need to be handled with kid gloves…but there is a level and I don't think so many professionals that I have come across, don't know how to find that level. They are so caught up with the terminologies and physiologies, and the psychologies of everything that they actually forget that they are talking to a person with feelings who actually go home and struggle to live on a daily basis. …it's kind of dismissive…then there's the authoritarian who sort of talks down to you…"* [Lynn, 28yrs]

> *"the new consultant, I've only met her once, and they always seem like they're in a bit of a rush which is quite annoying...its often after I leave that I think of something that I want to ask and then like oh God I'm going to have to wait for another six months before I go and see them."* [Lara, 17yrs]

The young people often reported feeling invisible with doctors not listening to the young person, talking to parents rather than them.

> *"When I was 15 my mum was going into the consultations with me, yes, most of the information was going to her rather than me. I didn't really feel like I was part of the consultation or part of the decision making process. You know I was the one who was having the seizures and taking the tablets, but I wasn't really involved..."* [Catherine, 29yrs]

> *"They [the doctors] go OK you've got sickle cell disease you need morphine., and you are like well I told you that when I first came in. So sometimes they don't want to hear it from you.* "[Helene, 23yrs]

Some also reported problems that "mum" had experienced: *"…it took four years for my mum to get the doctors to pay attention to the fact that I was really quite ill. A lot of the time they were blaming mum for being neurotic."* [Kate, 21yrs]. These quotes represent what Clarke (2005) calls sites of silence, or

silent voices, individuals silenced by powerful others within the situation. The oppression leads to frustrations and barriers to communication (Quill, 1989; Berry, 2006):

> *"I want to say to them [doctors] just listen to what I am saying and try to make it easier for me to explain, and don't just like make judgments on who you think I am."* [Miriam, 19yrs]

> *"…you get so frustrated trying to explain it so many times to so many different professionals. Each have their own agenda, have their own specialist subject, have their own specialist area of your body that they want to analyse that they don't look at the bigger picture in the first place, they look at the little sections and don't put it all together, then it tires you out and you end up getting nowhere."* [Lynn, 28yrs].

A number of the young people reported much more positive experiences:

> *"The nurses were really helpful, when I had down times they'd sit with me and you know they'd explain everything "They'd always be very good. They'd always spoke to me and my mum rather than just my mum."* [Donna, 18yrs]

> *"I've always had an open relationship with them [the doctors]. Just email them. Ring them up if I need any help. I've always been open with them…felt able to talk to them.* [Joseph, 17yrs]

> *"I can email my doctor, I wouldn't be able to do that five years ago. I mean that is how good a relationship I have got. I am close to the department and if I have got any problems or want to ask questions I can email. And they will get back to you the same day, you know, but if you get anything I just ask".* DavidB. 23yrs

The young people frequently reported the value of information sources from the Internet.

> *"The Internet has been a great resource particularly for finding out what medicines have side effects…If you just put it on the Internet there's lots of, you know, material out there …So I'd say that the Internet's been the main secondary source of information apart from the hospital."* [Joseph, 17yrs]

> *"I've looked around on the Internet and read different articles and in fact my GPs' emailed me things…I think it's really important… It's profound when you're in a world of grey or you know or perceived black, sometimes it can be you know really enlightening. It makes a huge difference…"* [Lynn, 28yrs].

> *"We started looking on the Internet… to find out if there were any kind of groups for just young people and that's when I got involved with AYM which is the Association of Young People with M.E. …And it was the first time that, you know, I actually had some leaflets that explained what M.E. is."* Miriam 28yrs

> *"I didn't really know much about it at the time, and as I found out more about it, I kind of got used to it [the condition] and became more comfortable with it".* Tomas 16yrs

As the quotes above illustrate, the "injections" of information can be self-administered, or by others such as healthcare provider, support groups, other people with the same illness. Tomas's quote evidences the relationship between having information and being able to cope, showing that once the young people accept their illness they begin to move on from any earlier feeling of uncertainly, fear or misunderstanding. This is supported in the literature where Pifalo et al., (1997) claimed that 52% of the people he studied receiving consumer health information said that it reduced their anxiety regarding their health concern. A key aspect of information acquisition, and the absorption of that information, is critical to the coping process as individuals become more knowledgeable and less uncertain (Lewis et al. 2010). The young people take information from their various interactions, and use this in combination with their own experiences.

> *"I've learnt from experience. …Sometimes you don't want to listen to your mum, you don't want to listen to the doctors. So you experience it for yourself . "So the doctors have never had to encourage me, I've learnt from experience."* [Helene, 23yrs].

> *"I sometimes find it hard to get a balance…I find myself getting disappointed with my body when it doesn't support me all the time… And I kind of learnt through what I can and can't do and I've learnt through the experience of it all."* [Sophie, 19yrs]

A strong theme in the data was the importance of finding out for themselves what they can and can't do, and feeling confident with their own capabilities

The information-coping trajectory – Position 4

- **Information health**. When a person has the information they need.

Knowledge is gained as a result of the learning experience which builds confidence. Sixteen of the young people identified a growth in confidence, and what could be interpreted as "information health". With the increased confidence, and support networks came acceptance, the ability to cope, and the ability to find practical solutions to everyday problems. Bury (1991) terms this as "legitimation" where individuals strive to gain a measure of control over their conditions by finding explanations that make sense in terms of their circumstances, get a proper perspective and establish an acceptable way of life.

> *"I'm, coping with it quite well…I tend instead of like fighting it like before...I tend to work with it. I've stopped thinking oh this is really a bad thing, because it's not. It's something you live with. I don't try to let it impact. I know it's very difficult…but I try to make the best of it now.* [Elizabeth, 22yrs].

> *"And when you're older you want to understand about why it's happening and, so you can be in control of it I suppose."* Nicola 24yrs

Ongoing relationships with health professionals were very important in coping. A number of the young people started to manage their communications with health professionals and take more control.

> *"They talk to me now…I think they find now that if they talk straight to the person, like the child, that they are like looking after then they could get through to them better than their parents telling them because they [the parents] won't tell you the full story…".* [Tomas, 16yrs]

"I chose a certain consultant…I found that I got on with him a lot better than I did the others. I think it was just the way he explained things and he tended to speak to me, like I was an adult." [Donna, 18yrs]

It has long been accepted in the literature that communication, and information behaviour are complex inter-related fields with researchers identifying that there is potential for communication problems to arise that might include misunderstandings and conflict (Dervin, 1976; Wilson, 1999B). Some of the young people reported having acquired the knowledge and experience to deal with their conditions that they experienced conflict with health professionals when trying to negotiate their healthcare frequently having to "fight" to be listened to.

"Fight very hard for what you want and what you don't… I had to fight to get off that drug. But you have to keep at it because it's your own body…and they will, they will listen to you. [Sara, 21yrs].

"I just wanted to scream at them, and say. No that's not what's happening…just listen to what I'm saying…" [Lynn, 28yrs]

Being treated with sensitivity and understanding was appreciated in these negotiated communications. Communication issues were expressed very clearly and strongly by the young people. They wanted to be talked to, not about, or over. They wanted to be acknowledged, and to take part in decision making, something reinforced in the literature (Wilson, 1999A; Jacobson et al., 2001; Decker et al. 2007). There were also occasions when they would have preferred a private consultation without mum so they could discuss "embarrassing" issues. Without this opportunity, young health consumers are forced to sources such as the Internet to seek support or advice (Skinner et al. 2003).

"I think doctors and nurses need to be sensitive to not only what young people are saying but to what they're not saying. Because there are lots of issues that you know it's embarrassing to talk about like your body, and like sex, and like alcohol. And there may be lots of issues that are upsetting young people but that they feel too embarrassed or too intimidate to actually tell their doctor." [Catherine, 29yrs].

"Doctors sometimes can be quite clinical about things and sort of forget that you are a human being and just see you as a condition…they see you as your illness and not as your person." [Lara, 17yrs]

At this stage there was very much a sense of developing maturity, a more developed understanding, and an increased sense of being in control, and having "information health", and having the ability to cope much better than reported in earlier stages of the illness experience.

The information-coping trajectory - Position 5

- **Information donor.** When a person has information that they can share to bring others to information health.

All the young people wanted to share their knowledge and experience and help others shown by their contribution to the Youthhealthtalk project, a number (10) had chosen to share their experiences in other ways by giving advice to others sometimes through work with charities, and support groups.

> [Sharing knowledge and experiences] *"because I was more stable about my epilepsy, because I felt more, like because I understood it better and I'd lived with it for a few years … I'd got over all of my anxieties about it so much, and I think that made it easier for me to explain to him [another young person with epilepsy] that it was okay, like and, It's nothing to be scared of and, it shouldn't stop us doing anything".* Lara 24yrs

> *"Yeah just talk to other people about it[asthma] and if you come to use the Kick Asthma holiday camps they are really useful. I really recommend it. I think the maximum age is 17 but you can also help as a volunteer and learn stuff through doing that".* David 18yrs

Having absorbed information from others, and gained knowledge of their conditions either from experience, or from what Rycroft-Malone et al. (2004) call practical knowledge, or from research, the young people reported becoming information providers themselves, wanting to share their knowledge, wisdom, expertise, and give advice. This advice ranged from practical tips such as keeping appointments to psychological support for example keeping positive. A key theme was the need to "fight". The young people showed a progression and developing maturity.

> *"You have to go through it, you have to fight it. You never give up."* [Hassan, 18yrs]

> *"All the facilities and the people around you are there to help you, just take advantage of them.* [Kate, 21yrs]

> *"The biggest advice I would give is to be honest… be honest with yourself"* [Miriam, 19yrs]

One young person spoke of acquired "wisdom" [Misha, 17yrs] and was eager to share this wisdom, whilst Hassan, had decided to write a book illustrating his experiences: "*I can show the people more hope, more inspiration, more courage. If you are truly courageous you can't just give up your life. I'm going to show this from my book".*

Throughout their experiences the young people identified the importance of having the right information, enough information, and having that information communicated effectively with sensitivity toward the individual, their situation, and their knowledge and opinions. These findings relate well to the knowledge exchange processes outlined by Lewis et al. (2010), identifying the positive and negative influences in the healthcare content, and the inabilities to cope experienced by young people who felt uninformed, versus the increased confidence experienced and improved quality of life when young people become knowledgeable about their condition.

Summary of key findings

A principal finding was that as the young people became more informed about their health conditions, and gained knowledge and understanding both about their illnesses and their own bodies and boundaries, then their confidence and capacity to cope with their conditions increased as illustrated in the information trajectory (Figure 3).

The information they needed was gathered from a variety of sources of evidence as they required injection of information to counteract any information deficiency and feelings of being ill-informed; from their interactions with health professionals, support groups and charities, the Internet, other young people suffering with similar conditions, family and friends, and from their own experiences. They used this information to build their own knowledge base attaining information health and supporting their health decision making. They relied not just on their own capabilities, but those of their support networks.

In their journey from initial diagnosis to accepting their conditions, and coping with life on a daily basis they went through a series of negative and positive emotions and experiences which they reflected and learnt from. The experiences they had varied, sometimes positive, sometimes negative, and their needs and perspectives changed as they matured and learnt from their experiences. The young people in this study report on a number of difficulties that can occur in the relationships between them and healthcare staff particularly. Communication disconnects, and different constructions of phenomena can contribute to, or cause misunderstandings to occur

The young people often wanted to share their knowledge with others and they became information providers or information donors passing on tips, knowledge and advice to others.

The idea of information making a huge difference is a key issue from this research. Feeling informed, gaining, knowledge about the condition, and learning from experience about personal boundaries were identified as critical to learning to live and cope with the health conditions, After the shock of being diagnosed the young people experienced a range of emotions. Their stories show shock, fear, anger, denial, rebellion, frustration, accepting what is happening, gradually developing confidence in dealing with their conditions, and for some individuals this resulting in mixed emotions as they struggled to adjust to their new found situations, and come to terms with their health conditions.

The effective communication of information has a key role to play in building the capacity to cope, strengthened by information, knowledge and experience as illustrated within the data.

Conclusions and recommendations for further research

This paper has explored the relationship between information and coping for this group of young people coping with long term illness. It has considered the information and knowledge experiences verbalized by the young people in an analysis of thirty interviews, using Situational Analysis. The mapping techniques of Situational Analysis aided the visualisation and modeling of an information-coping trajectory presented in this paper as contribution to the research in information behavior.

The young people coping with long term health conditions are at the centre of this situation. They are part of social worlds that come together with other individuals and social groups to engage in health discourse within a range of personal and institutional arenas where they obtain social support including information. The approach in this study has identified those social worlds and established categories of both personal, and institutional social worlds/arenas for health discourse. The Information and communication experiences have been explored through the narratives of the young people. The young people share a common experience of "coping with illness", yet there are different and sometimes conflicting experiences and discourses. Areas of conflict have emerged with power struggles being played out within the institutional healthcare arena where negotiations often took place regarding health care decisions,

Many of the young people reported that Information, and knowledge, empowered them, making them feel more confident to negotiate their own position and take more control over their situation. Information and knowledge can be presented as non-human actants that change the behaviour of the young people as they develop informed coping strategies. Health information is key to change, and has been identified as not being solely the remit of the health care provider, but being a wider community responsibility with young people gathering information from a wide range of sources; their social support network being multi-dimensional.

For the young people the illness had changed their lives. They found themselves having to re-negotiate their social position, so that they once more fitted in with their social groups. Mostly, the young people found that friends, family, and other social networks were supportive, and helped them cope with the changed situation they found themselves in through ill health.

This study has enabled us to understand more clearly the shifting position that the young person takes in relation to information, knowledge, and their ability to cope as illustrated in the positional map, Figure 3, showing that as the young people became more informed about their health conditions, and gained knowledge and understanding both about their illnesses and their own bodies and boundaries, then their confidence and capacity to cope with their conditions increased. This progression has been identified as the information-coping trajectory.

The study is limited by its use of thirty narratives, yet the data is rich, and the method has qualitative rigour through its iterative processes, the systematic approach to analytical data mapping, and the reflexive approach through analytical memos and review. Not all the issues uncovered could be discussed within this paper. Wider studies would enhance further the understanding of the situation with interviews from representatives of all groups within the situation rather than viewing the situation from the young persons' perspective, yet this perspective is valuable as it is often neglected.

This study has value in its methodological approach presenting a rich perspective of the young people in their wider social situation which could have impact, and contribute across a number of domains, health care, communication theory, sociology, and information studies. It illustrates the value of this type of research approach for exploring a situation in context. It shows the changing needs of the young people as they learn to cope with their illness and build their personalised knowledge base and support network increasing their ability to cope. This study shows the need for sensitivity in the communication process with young people at a difficult time in their lives. The study supports the requirement for healthcare professionals to be sensitive to the changing information needs, and to have on their radar an acknowledgement of valuable information, knowledge and evidence other than traditional research i.e. their own clinical experience, and the patient/parent experiences which need time to be listened to, and their needs acted on.

Studies have shown that health professionals recognize that teenage health is a specialism, and are open to training (Sanci et al.,2000). Viner and Barker (2005) offer a number of suggestions to improve efficiency in youth health that include a separate health policy, developing more research programmes in youth health, improving health indicators in this area, and improving services to encourage engagement with young people. However, it is important to understand the wider situation, the relationships that occur, the wide range of sources of information and knowledge that young people and the health carers use to create and evidence base on which make health decisions, and the complexity

of the information needs of young people on their journey through this stage of their lives dealing with a long term health condition.

Listening to the narratives of the young people in this study has been a moving and enlightening experience. It needs time - and that is a critical issue, to build time into the lives of health professionals to be able to listen to and explore the patient experience more fully for effective communication, and as a source of evidence to support health decision making,

References

Barker, G. G., Olukoya, A. A., and Aggleton, P. P. (2005), "Young people, social support and help-seeking", *International Journal of Adolescent Medicine and Health,* Vol. 17 No 4, pp. 315-355.

Barnett, M. (2002), "Effect of breaking bad news on patients' perceptions of doctors", *Journal of Royal Society of Medicine*, Vol. 95 No. 7, pp. 343-347.

Bawden, D. and Robinson, L. (2012) *Introduction to information Science.* Facet: London.

Berry, D. (2006), *Healthcare communication: theory and practice*, Open University Press, Maidenhead.

Bone, D. (2002), "Dilemmas of emotion work in nursing: Under market-driven health care", *International Journal of Public Sector Management*, Vol. 15 No. 2, pp. 140-150.

Brashers, D. and Jackson, S. (1999) "Changing conceptions of "message effects": A 24-year overview". *Human Communication Review*. Vol. 25 No. 4, pp. 457-477.

Brashers, D., Neidig, J.L. Reynolds, N.R., Haas, S. (1998) "Uncertainty in illness across the HIV/AIDS trajectory". *Journal of the Association of Nurses in Aids Care*. Vol. 9 No. 1, pp. 66-77.

Brashers, D. Haas, S.M., Neidig, J.L. and Rintamaki, L.S. (2002) "Social activism, self-advocacy, and coping with HIV illness". *Journal of Social and Personal Relationships*. Vol. 19 No, 1, pp. 113-132.

Brashers, D.E. , Neidig, J.L. and Goldsmith, D.J. (2004) "Social support and the management of uncertainty for people living with HIV and Aids". *Health Communication.* Vol. 16 No, 3, pp. 305-331.

Bryman, A. (2008) *Social Research Methods*. 3rd Ed. Oxford University Press: Oxford.

Buckloh, L. M., Lochrie, L. S., Antal, H., Milkes, A., Canas, J. J., Hutchinson, S., and Wysocki, T. (2008), "Diabetes complications in youth: Qualitative analysis of parent's perspectives of family learning and knowledge", *Diabetes Care*, Vol. 31 No. 8, pp. 1516-1520.

Buckman, R. (1984), "Breaking bad news: Why is it so difficult?" *British Medical Journal,* Vol. 288 No. 6430, pp. 1597-1599.

Burns, J. R., and Rapee, R. M. (2006), "Adolescent mental health literacy: Young people's knowledge of depression and help seeking", *Journal of Adolescence*, Vol. 29 No. 2, pp. 225-239.

Bury, M. (1991), "The sociology of chronic illness: a review of research and prospects", *The Sociology of Health and Illness*. Vol. 13 No. 4, pp. 451-468.

Canam, C. (1993), "Common adaptive tasks facing parents of children with chronic conditions", *Journal of Advanced Nursing,* Vol. 18 No. 1, pp. 46–53.

Case, D., Andrews, J. E., Johnson, J. D., and Allard, S. L. (2005), "Avoiding versus seeking: the relationship of information seeking to avoidance, blunting, coping, dissonance, and related concepts", *Journal of Medical Library Association*, Vol. 93 No. 3, pp. 353–362.

Case, D. (2012) *Looking for information: A survey of research on information seeking, needs and behaviour*. (3rd Ed.). Emerald: Bingley.

Chappie, A., Ziebland, S., and McPherson, A. (2004), "Stigma, shame, and blame experienced by patients with lung cancer: qualitative study", *British Medical Journal,* Vol. 327 No. 7454 pp. 1470 URL: http://www.bmj.com/content/328/7454/1470.full Accessed 2nd November 2011.

Checkland, P. and Scholes, J. (1999) *Soft Systems Methodology in Action*. Wiley: Chichester.

Clarke, A. (1991), "Social Worlds/Arenas Theory as Organisational Theory", Maines, D. (Ed.), *Social organization and social process: Essays in honor of Anselm Strauss*, Aldine de Gruyter, New York, pp. 119-158.

Clarke, A. (2003), "Situational Analysis: Grounded theory after the Postmodern turn". *Symbolic Interaction*, Vol. 26 No. 4, pp. 553-576.

Clarke, A. (2005), *Situational Analysis: Grounded theory after the Postmodern turn*. Sage, Thousand Oaks.

Clarke, A. and Montini, T. (1993), "The many faces of RU486: Tales of situated knowledges and technological contestations", *Science Technology and Human Values* Vol. 18 No. 1, pp. 42-78.

Coppa, K., & Boyle, F. M. (2003), "The role of self-help groups in chronic illness management: a qualitative study", *Australian Journal of Primary Health*, Vol. 9 No. 2/3, pp. 68-74.

Corbin, J., & Strauss, A. (1991) "A nursing model for chronic illness management based upon the Trajectory Framework". *Scholarly Inquiry for Nursing Practice*. Vol. 5, pp. 155-174.

Decker, C., Haase, J. E. & Bell, C. J. (2007). „Uncertainty in adolescents and young adults with cancer". *Oncology Nursing Forum.* Vol. 34 No. 3, pp. 681-688.

Decker, C., Phillips, C. R., and Haase, J. E. (2004), "Information needs of adolescents with cancer", *Journal of Pediatric Oncology Nursing,* Vol. 21 No. 6, pp. 327-334.

Department of Health (2006), *Transition: moving on well. A good practice guide for health professionals and their partners on transition planning for young people with complex health needs or a disability*. DoH Partnership for Children, Families and maternity/CNO Directive. Department of Health, London.

Dervin, B. (1976), "Strategies for dealing with human information needs: Information or communication?" *Journal of Broadcasting*, Vol 20 No. 3, pp. 324-333.

Ekberg, J., Ericson, L., Timpka, T., and Eriksson, H. (2010), "Web 2.0 systems supporting childhood chronic disease management: Design guidelines based on information behaviour and social learning", *Journal of Medical Systems*, Vol. 34 No. 2, pp. 107-117.

Ellis, D. (1989) "A behavioural approach to information retrieval system design". *Journal of Documentation*. Vol. 45 No. 3, pp.171-212.

Fisher, K. E., Erdelez, S., and McKechnie, L. (2005) *Theories of information behaviour*. Information Today: New Jersey.

Folkman, S., & Lazarus, R. S. (1985). If it changes it must be a process: A study of emotion and coping during three stages of a college examination. *Journal of Personality and Social Psychology*, Vol. 48, (1) pp. 150-170.

Folkman, S., and Lazarus, R. S. (1988). *Manual for the Ways of Coping Questionnaire.* Consulting Psychology Press: Palo Alto, CA.

Foster, A. (2004) "A non-linear model of information seeking behavior". *Journal of the American Society for Information Science and Technology.* Vol. 55 No. 3, pp. 228-37.

Franck, L., Noble, G., and McEvoy, M. (2008), "Enquiring minds want to know: topics requested by users of a children's health information website", *Patient Education and Counseling*, Vol. 72 No. 1, pp. 168-171.

Frydenberg, E. (2008) Adolescent coping: Advances in theory, research and practice. Routledge: Hove.

Fudge, E., and Mason, P. (2004), "Consulting with young people about service guidelines relating to parental mental illness", *Australian e-Journal for the Advancement of Mental Health (AeJAMH),* 3(2), 1-9. URL: http://www.atypon-link.com/EMP/doi/abs/10.5172/jamh.3.2.50 Accessed 2nd November 2011.

Garcia, C. (2010) "Conceptualization and measurement of coping during adolescence: A review of the literature". *Journal of Nursing Scholarship.* Vol. 42 No. 2, pp. 166-185.

Gibbs, R. W., Leggitt, J. S., & Turner, E. A. (2002), "What's special about figurative language in emotional communication?" In Fussell, S. R. (Ed.), *The verbal communication of emotions: Interdisciplinary perspectives*, Lawrence Erlbaum, London, pp. 114- 136.

Glaser, B. and Strauss, A. (1965) *Time for Dying.* Aldine: Chicago.

Glaser, B. and Strauss, A. (1968) *Awareness of Dying.* Aldine: Chicago.

Goldsmith, D. J. and Fitch, K. (1997) "The normative context of advice and social support". *Human Communication Research.* Vol. 23 No.4, pp. 454-476.

Henly, S. J. Wyman, J.F., Findorff, M.J. (2011) "Health and illness over time. The trajectory perspective in nursing science". *Nursing Research*, Vol. 60 No. 3 Supp, pp. S5-14.

Hobfoll, S.E., Briggs-Phillips, M., and Stines, L.R. (2003) Fact or artifact: The relationship of hope to a caravan of resources. In R. Jacoby & G. Keinan (Eds.). *Between stress and hope: From a disease-centered to a health-centered perspective* (pp. 81-104). Praeger: Westport, CT.

Hock, M., & Krohne, H. W. (2004). "Coping with threat and memory for ambiguous information: Testing the repressive discontinuity hypothesis". *Emotion*, Vol. 4, pp. 65– 86

Hokkanen. H., Eriksson, E., Ahonen, O., and Salantera, S. (2004), "Adolescents with cancer: experience of life and how it could be made easier", *Cancer Nursing,* Vol. 27 No. 4, 325-335.

Horowitz, M. J. (1976) *Stress Response Syndromes*. Aronson: Northvale, NJ.

Hummelinck, A., and Pollock, K. (2006), "Parents' information needs about the treatment of their chronically ill child: A qualitative study", *Patient Education and Counseling*, Vol. 62 No. 2, pp. 228-234.

Iles, N., and Lowton, K. (2010), "What is the perceived nature of parental care and support for young people with cystic fibrosis as they enter adult health services?", *Health and Social Care in the Community,* Vol. 18 No. 1, pp. 21–29.

Jacobson, L., Richardson, G., Parry-Langdon, N., and Donovan, C. (2001), "How do teenagers and primary healthcare providers view each other? An overview of key themes", *British Journal of General Practice*. Vol. 51 No. 471, pp. 811-816.

Jakobson, R. (1971). *The fundamentals of language.* Mouton de Gruyter, Berlin.

James, A., and Prout, A. (1990), *Constructing and reconstructing childhood.* Falmer Press, Basingstoke.

Jerret, M., and Costello, E. (1996), "Gaining control. Parents' experiences of accommodating children's asthma", *Clinical Nursing Research.* Vol. 5 No. 3, pp. 294–309.

Jones, R., Finlay, F., Simpson, N., and Kreitman, T. (1997), "How can adolescents' health needs and concerns best be met?" *British Journal of General Practice,* Vol. 47 No. 423, pp. 631-634.

Kaplan, B. H., Cassel, J. C., and Gore, S. (1977), "Social support and health", *Medical Care,* Vol. 15 No. 5, pp. 47-58.

Kefford, C. H., Trevana, L. J., and Willcock, S. M. (2005), "Breaking away from the medical model: perceptions of health and health care in suburban Sydney youth", *The Medical Journal of Australia.* Vol. 183 No. 8, pp. 418-421.

Kübler-Ross, E. (1969), *On death and dying*. Routledge: London.

Latour, B. (2004), *The Politics of Nature: How to Bring Sciences into Democracy,* Harvard University Press, Cambridge, Mass.

Lazarus, R. (1988) *Stress and emotion: A new synthesis*. Free Association Books: London.

Lazarus, R. S. (2000) Toward better research on stress and coping. *American Psychologist.* 55 (6) 665-673.

Lazarus, R. S. (2006) *Stress and emotion*. Springer: New York.

Lazarus, R. S. and Folkman, S. (1984) Stress, appraisal, and coping. Springer: New York.

Lèvi-Strauss, C. (1994), *The Savage Mind,* Oxford University Press, Oxford.

Lewis, S., Noyes, N., and Mackereth, S. (2010), "Knowledge and information needs of young people with epilepsy and their parents: Mixed-methods systematic review", *BMC Pediatrics,* Vol. 10 No. 103. URL: http://www.biomedcentral.com/1471-2431/10/103 Accessed 2nd November 2011.

Mayall B. (1996), *Children, health and the social order,* Open University Press, Buckingham.

Maciejewski, P. K., Zhang, B., Block, S. D., Prigerson, H. G. (2007) "An empirical examination of the stage theory of grief". *Journal of the American Medical Association* (JAMA), Vol. 297 No. 7 pp. 716-23.

Miller, S. M. (1980) When is a little information a dangerous thing? Coping with stressful events by monitoring versus blunting. In S. Levine, and H. Ursing. (Eds), Coping and health (pp145-169). Plenum: New York.

Mills, J., Francis, K., and Bonner, A., (2007), "Live my work: rural nurses and their multiple perspectives of self". *Journal of Advanced Nursing,* Vol. 59 No. 6, pp. 583-590.

Neville, K. (1998) "The relationships among uncertainty, social support, and psychological distress in adolescents recently diagnosed with cancer". *Journal of Pediatric Oncology Nursing*, Vol. 15 No. 1, pp 37-46.

Nuutila, L., and Salanterä, S. (2006), "Children with a Long-Term Illness: Parents' Experiences of Care", *Journal of Pediatric Nursing*, Vol. 21 No. 2, pp. 153-160.

Olsson, C. A., Boyce, M., Toumbourou, J. W., and Sawyer, S. M. (2005), "Chronic illness in adolescents: the role of peer support groups", *Clinical Child Psycholology & Psychiatry*, Vol. 10 No. 1, pp. 78-87.

Outhwaite, W., & Turner, S. (2007), *The Sage Handbook of Social Science Methodology,* Sage, London.

Pain, H. (1999), "Coping with a child with disabilities from the parents' perspective: The function of information", *Child Care, Health and Development,* Vol. 25 No. 4, pp. 299-312.

Parker, J. D. A., & Endler, N. S. (1992). "Coping with coping assessment: A critical review", *European Journal of Personality*, Vol. 6, pp. 321-344.

Pifalo, V., Hollander, S., Henderson, C. L., DeSalvo, P., and Gill, G. (1997), "The impact of consumer health information provided by libraries: the Delaware experience*", Bulletin of the Medical Library Association.* Vol. 85 No. 1, pp. 16–22.

Quil, T. E. (1989), "Recognizing and Adjusting to Barriers in Doctor-Patient Communication", *Annals of Internal Medicine*, Vol. 111 No. 1, pp. 51-57.

Dando, T. (1984) *Grief, dying, and death: Clinical interventions for caregivers*. Research Press: Champaign, Ill.

Rickwood, D. J., Deane, F. P., and Wilson, C. J. (2007), "When and how do young people seek professional help for mental health problems?" *Medical Journal of America, Vol.* 187 No. 7, pp. S35-S39.

Rycroft-Malone, J., Seers, K., Titchen, A., Harvey, G., Kitson, A., and McCormick, B. (2004), "What counts as evidence in evidence-based practice?" *Journal of Advanced Nursing.* Vol. 47 No 1, pp. 81-90.

Sanci, L. A., Coffey, C. M. M., Veit, F. C. M., Carr-Gregg, M. Patton, G. C., Day, N., and Bowes, G. (2000), "Evaluation of the effectiveness of an educational intervention for general practitioners in adolescent health care: randomised controlled trial", *British Medical Journal,* Vol. 320 No.7229, pp. 224–230.

Sastre, M. T., Sorum, P.C., and Millet, E. (2011), "Breaking bad news: The patient's viewpoint". *Health Communication,* Vol. 26 No. 7, pp. 649-655.

Saussure, F. (1983), *Course in general linguistics*, Duckworth: London.

Seiffe-Krenke, I. and Beyers, W. (2005) "Coping trajectories from adolescence to young adulthood: Links to attachment state of mind". *Journal of Research on Adolescence.* Vol. 15 No. 4, pp. 561-582.

Shontz, F. C. (1975) *The psychological aspects of physical illness and disability.* Macmillan: New York.

Skinner, H., Biscope, S., Poland, B., and Goldberg, E. (2003), "How adolescents use technology for health information: implications for health professionals from focus group studies", *Journal of Medical Internet Research,* Vol. 5 No. 4, pp. e32.

Sonnenwald, D. (2005) Information Horizons. In. Fisher, K., Erdelez, A. And McKechnie, L. (Eds.) *Theories of Information Behaviour*. New Jersey: Information Today. pp. 191-197.

Strauss, A., Schatzman, L., Bucher, R., Ehrlich, D., and Sabshin, M. (1981), *Psychiatric ideologies and institutions,* Transaction Books, New Brunswick, NJ.

Thorne, S., Con, A., McGuiness, L., McPherson, G., and Harris, S. R. (2004), "Health Care Communication Issues in Multiple Sclerosis: An Interpretive Description", *Qualitative Health Research,* Vol. 14 No. 1, pp. 5-22.

Vasconcelos, A. C. (2007), "The use of Grounded Theory and Arenas/Social Worlds Theory in discourse studies: A case study on the discursive adaptation of information systems", *Electronic Journal of Business Research Methods*, Vol. 5 No. 2, pp. 125-136.

Vasconcelos, A. C., Sen, B., Rosa, A., & Ellis, D. (2012) "Elaborations of Grounded Theory in information research: Arenas/Social Worlds Theory, Discourse and Situational Analysis", *Library and Information Research.* Vol. 36 No. 12, pp. 120-146.

Verma, S. (1989*), Everybody's different, everybody's the same: effective practice in integration.* Ministry of Education, Melbourne, Victoria.

Viner, R. M., and Barker, M. (2005), "Young people's health: The need for action", *British Medical Journal,* Vol. 330 No. 7496, pp. 901-903.

Whalen, S., Splendorio, D., & Chiariello, S. (2007), *Tools for teaching health : interactive strategies to promote health literacy and life skills in adolescents and young adults.* Jossey-Bass, San Francisco.

Weiner, C. (1991), "Arenas and careers: the complex interweaving of personal and organizational destiny". In Maines, D. (Ed.), *Social organization and social process: Essays in honor of Anselm Strauss*, Aldine de Gruyter, New York, pp. 175-188.

Wilson, J. (1999A), "Acknowledging the expertise of patients and their organizations", *British Medical Journal,* Vol. 319 No. 7212, pp. 771.

Wilson, T. (1999B), "Models in Information behaviour research", *Journal of Documentation*. Vol. 55 No. 3, pp. 249-269.

Wortman, C. B. (2007) "The stage theory of grief". (Letters) *JAMA* Vol. 297 No. 24, pp. 2692-2694.

Young, B., Dixon-Woods, M., Windridge, K.C., and Heney, D., (2003), "Managing communication with young people who have a potentially life threatening chronic illness: qualitative study of patients and parents", *British Medical Journal*. Vol. 326 No. 7384, pp. 305.

Ziebland, S., and McPherson, A. (2006), "Making sense of qualitative data analysis: an introduction with illustrations from DIPEx (personal experiences of health and illness)", *Medical Education,* Vol. 40 No. 5, pp. 405-414.

Tables and charts in order of as they appear in the paper.

Table 1. Stages of coping: Selected theories from the literature.

| Model	Stages of coping
Frydenbrg (2008)	(1)Primary appraisal- of the situation: challenges, harm, threat loss etc (2) Secondary appraisal- of personal characteristics e.g. age, personality, temperament, hope, optimism (3)Tertiary appraisal-review of the outcomes as a result of previous behaviour
Hock and Krohne (2004)	(1)Attention orientation (2) Appraisal (3) Self regulation
Horowitz (1976)	(1)Outcry (2) Denial and intrusion (3) Working through Completion
Kubler-Ross (1969)	(1)Denial (2) Anger (3) Bargaining (4) Depression (5) Acceptance
Maciejewski et al. (2007)	(1)Disbelief (2) Yearning (3) Anger (4) Depression
Rando (1984)	(1) Recognise (2) React (3) Re-collect and re-experience (4) Relinquish (5) Readjust (6) Reinvest
Shontz (1975	(1)Shock (2) Encounter reaction: e.g. anxiety, grief, despair, fear (3) Retreat: denial, withdrawal (4) Reorientation
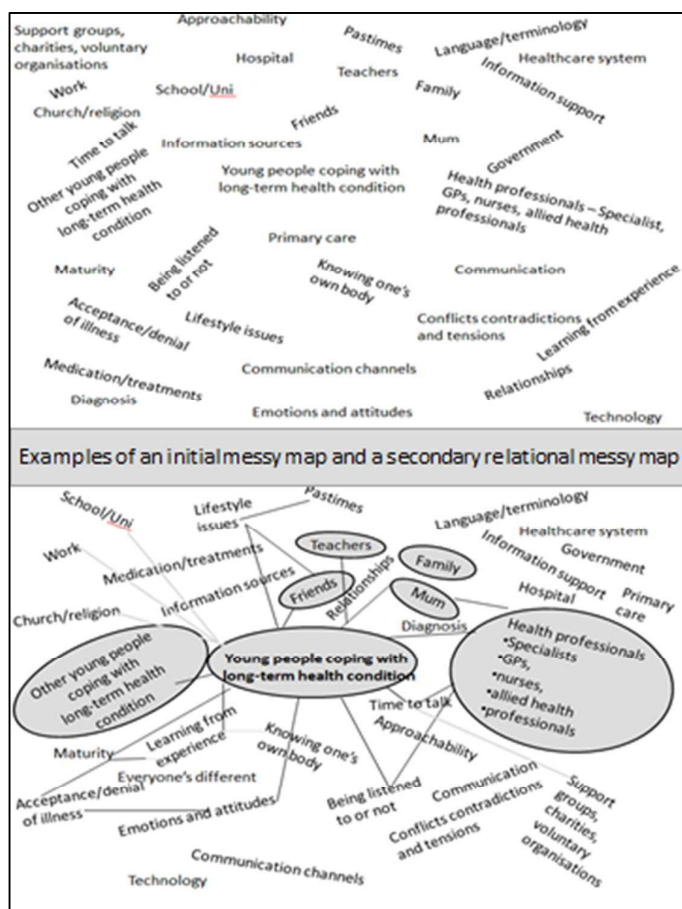
Figure 1. Early iterations of the messy map and relational messy map

Table 2. Ordered situational map. Young people coping with a long term health conditions, and their information, knowledge sharing, and communication experiences.

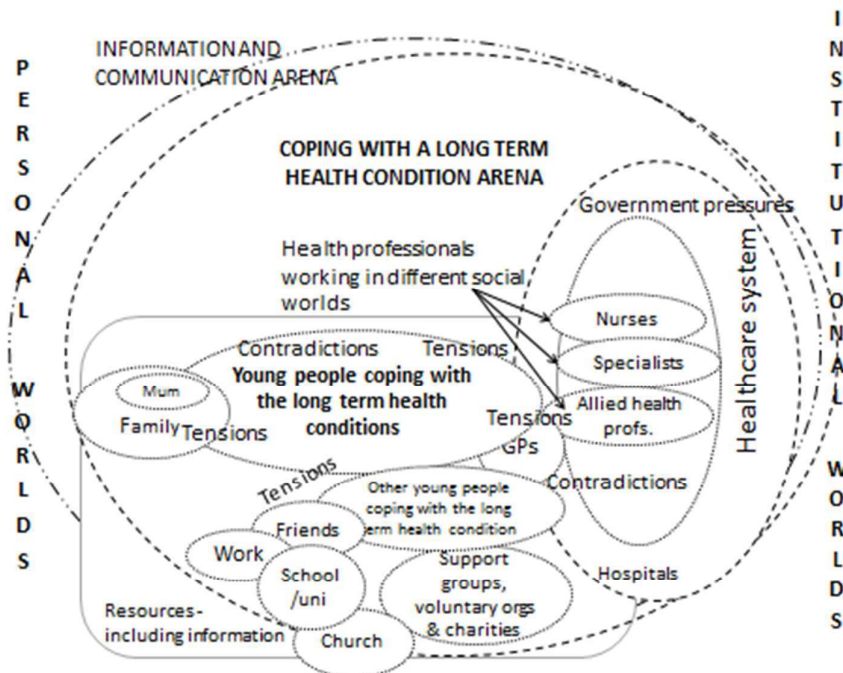|	
Individual Human Elements/Actors The young person coping with a long term health condition. Other young people coping with same health condition. Friends Family – mum, dad, sister, brother Teacher Health professional: Doctors – specialist, GP, nurse, other health professional e.g. dietician, physiotherapist	**Non-Human Elements/Actants** Information concepts, forms and resources Clear language/terminology Communication channels Technology, the Internet The media Medication and treatments Pastimes e.g. drugs, drink, smoking, sex, clubbing,
Collectives Human Elements/Actors Other young people coping with the same long term health condition. Friends & family Teachers Health professionals: Doctors – specialists, GPs, nurses, other health professionals e.g. dieticians, physiotherapists Health service and hospitals Support Groups, voluntary organizations, charities School, university, work Church Government	**Discursive Constructions of Individual and/or Collective Human Actors** Young person being "invisible". Everybody's different /patient uniqueness Specialists as "scary" "unapproachable" Specialists see the condition not the person Nurses as helpful Mum as support Friends as a form of support Health professionals as support Support groups as support networks Young person as information provider
Key events in the situation Diagnosis Acceptance of the health condition	**Implicated/Silent Actors/Actants** Silent voices of young people Silent voices of family
Political/Economic Elements Not enough people Funding issues Need for research	**Discursive Constructions of Non-Human Actants** Information as a form of social support Communication channels as enablers for accessing support Constructions of the health condition
Temporal Elements Time needed to talk Too much time taken to be given information Wasted time – through lost results Maturing of the young person	**Socio-cultural /Symbolic Elements** Young person needing to fit in – social acceptance Young people in society Illness
Major Issues/Debates (Usually Contested) Importance of communication Importance of being informed Importance of relationships and needing support Importance of healthy lifestyle	**Related Discourses (Historical Narrative, and/or Visual)** Discourses on individualism Discourses on health and illness Discourses on information, knowledge and communication Discourses on lifestyle Discourses about relationships and support
Other Kinds of Elements Personal attitudes and emotions Conflict	**Spatial Elements**

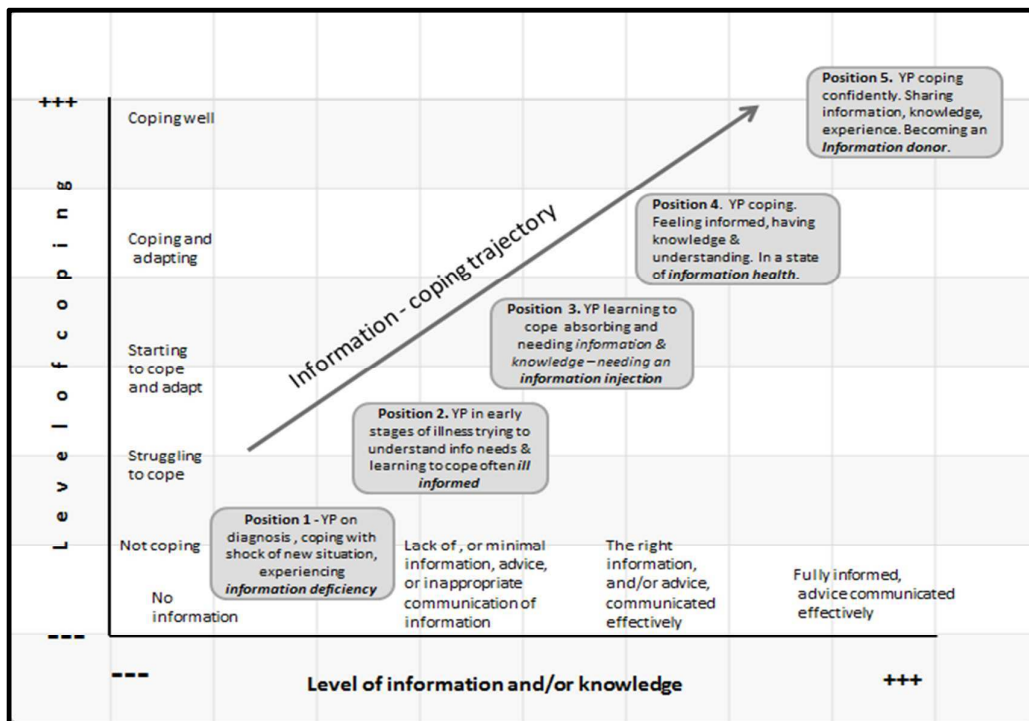**Figure 2.** Social worlds/arenas map for young people coping with long term health condition.

Figure 3. Positional map showing the relationship between the young peoples' levels of information and knowledge, and their ability to cope with long term health conditions. Their position changes as

they mature along their patient journey. We have plotted five key position, individuals may be positioned anywhere on the map. These key positions represent the information-coping trajectory.