



Caring for teenagers and young adults with cancer: A grounded theory study of network-focused nursing

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A B S T R A C T

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Teenagers and young adults (TYAs) are extremely vulnerable and dependant on a supportive social network when diagnosed with cancer and undergoing treatment.

Purpose: The aim of the study was to generate a substantive theory by exploring processes and strategies of oncology nurses engaged in a nursing programme, which aims at supporting these young patients and their significant others to maintain, establish and strengthen support from their social network during the treatment period.

Method: A grounded theory approach was used and data were generated through interviews, observations, informal conversations and documents. All nurses (7) from a Danish oncology youth unit participated.

Results: 'Bridging' was defined as the core concept in nurses' strategies aimed at creating a space for the TYAs' normal growth and development. By strategies of 'Tuning in', 'Framing the situation', 'Navigating towards the goal' and 'Connecting people' the nurses attempted to provide a foundation for the seriously ill TYAs to connect to their normal everyday life.

Conclusions: The study complements existing knowledge of caring for TYAs with cancer, showing how oncology nurses can use their knowledge and position to facilitate involvement of the patients' social network. It contributes with a theoretical framework for clinical practice that offers insight into an unexplored area of nursing. Network-focused nursing is a complex and demanding practice that needs to be addressed by nurses, educators, researchers and health policy makers.

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Introduction

Social support and contact with their social network is of major importance to teenagers and young adults (TYAs) with cancer. In this article, TYA refers to young people between 15 and 22 years. The availability of emotional, practical and informational support from family, friends, peers, healthcare professionals and other cancer patients becomes crucial when TYAs' life trajectories are disrupted due to cancer and long periods of treatment (Kyngas et al., 2001; Ishibashi, 2001; Ritchie, 2001a; Woodgate, 2006). Parents provide the most important social support, but as the cancer disease has an impact on the whole family, they all need support (Grootenhuis and Last, 1997; von Essen et al., 2001; Grinyer, 2002).

The importance of social support for these TYAs as well as their families is increasingly recognised in healthcare, emphasising that the care of TYAs with cancer needs to be age appropriate and tailored for this specific group of patients (Whelan, 2003; Albritton and Bleyer, 2003; Smith, 2004). However, little is known about how nurses in a hospital setting can contribute to meeting these needs.

Healthcare providers should be aware of how TYAs' developmental abilities and growth affect their cancer experience and how this experience affects their development (Albritton and Bleyer, 2003). Drawing on several studies Ritchie recommends a developmentally focused approach in caring for young people with cancer, which includes provision of social support. Maintaining their existing support systems by reinforcing them and by identifying possible gaps are key tasks for the healthcare team (Ritchie, 2001b). This is essential because TYAs in general are considered to go through a developmental phase characterised by significant changes in the biological and social domain and by emotional turmoil and behavioural inconsistencies (Christie and Viner, 2005; Radzik et al., 2008). In this transition

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between dependant childhood and independent young adulthood they become extremely vulnerable when diagnosed with cancer. Teenagers and young adults who are beginning to experience success in independent decision-making are thrown back into a dependant role with their significant others. Roles that they are just beginning to master such as student, recent graduate, new employee or new parent become uncertain and plans for the future seem impossible (Albritton and Bleyer, 2003). Good care for young people with cancer is therefore a broad, complex and multidimensional phenomenon (Hedström et al., 2004).

Worldwide, teenagers up until the age of 18 are usually treated in paediatric oncology settings. Consequently, most research investigating their care has been conducted in this environment. Several studies conclude that the care of TYAs can preferably be organised in dedicated units for TYAs where they will not feel too old or too young compared with the other patients and where they meet specialised multidisciplinary teams who base their care on the understanding of the unique needs and subculture of TYAs (Whelan, 2003; Wilkinson, 2003; Kelly et al., 2004).

Realising that an ordinary adult oncology ward was not able to meet the needs of TYAs and their significant others, a youth unit was established in 2000–2002 in a university hospital in Denmark. A nursing programme was developed that aimed to reduce the impairment of the disease and the treatment by helping the TYAs to maintain or establish a supportive social network (Hove et al., 2004).

In recognition of the potential of social support and the limited published knowledge about how to provide nursing care that reaches beyond individual patients and their significant others, we conducted a grounded theory study in this youth unit. The purpose was to generate a substantive theory that would conceptualise what happens when oncology nurses engage in supporting TYAs with cancer and their significant others to maintain, establish and strengthen social relationships and a social network during the treatment period. A social network can be defined as consisting of informal relationships, “individuals and linkages between individuals with whom one has a close family relation and/or affection” and formal relationships, that are “social relations due to one’s position and role in society” (Due et al., 1999). This article presents processes and strategies involved when oncology nurses in a youth unit proactively perform network-focused nursing and the nurses’ thoughts about the actions and interactions.

Methods

The method used was classic grounded theory (Glaser and Strauss, 1967; Glaser, 1978) combined with a constructivist approach to emphasise that people construct their realities through interpretive processes and individual and collective actions (Charmaz, 2006; Bryant and Charmaz, 2007). In the research situation this means that the reality of the participant and the reality of the researcher are both influenced by their interactions, which shape how they construct the meaning of their realities and how the viewer and the viewed mutually construct knowledge. The researcher offers an interpretive portrayal of the studied world that accounts for her reflexive role in the data construction and the theory developed (Charmaz, 2006). Thus, the researcher recognises that she brings to the study her general perspectives of her discipline, her philosophical, theoretical, substantive and methodological proclivities, her particular research interests and her biography (Charmaz, 1990). We were mindful of this and strove to carefully examine the emerging ideas and to remain as open as possible.

In-depth interviews, participant observations, informal conversations and documents were used to obtain rich and comprehensive descriptions. Data generation and analysis alternated. This

allowed for a theoretical sampling process where ongoing comparative analysis guided increasingly focused data generation.

Setting and participants

The study took place in the youth unit of the department of oncology in a university hospital in Denmark. The department is one of five oncology treatment centres in Denmark that undertake non-surgical cancer treatment and out-patient follow up. Fifteen–twenty-two year old TYAs with solid cancer tumours are admitted to treatment and care at this youth unit, which is part of an adult ward and comprises two 2-bedded rooms and a “Youth corner” in the sitting room. On average eight to ten new patients are admitted per year. Most of them are male TYAs as osteo-sarcoma and testicular cancer are frequent diagnoses in the youth unit.

The network-focused nursing programme, developed in the youth unit, implies new ways of approaching the young patient, the significant others (parents and on rare occasions a partner) and the wider informal and formal social network important to the young patient and the significant others (other family members, friends, social worker, general practitioner, school teacher etc.). Network meetings and “parent-free time” are key aspects of this nursing programme, aimed at maintaining and mobilising a supportive social network. Network meetings are meetings chaired by the nurses and arranged in cooperation with and for the individual TYA. Significant others, friends and family members are invited as well as professionals such as the consultant, the physiotherapist, a school teacher, a social worker and the TYA’s general practitioner. Everybody is there for the TYA and to get information and discuss how the individuals in this informal and formal social network might help and support the young person (Hove et al., 2004). Parent-free time is hours where the significant other leaves the TYA’s bedside and where the parties, if they wish, can talk to the nurse alone.

All presently employed nurses (4) and nurses who had left the youth unit within 1 year (3) were eligible for inclusion and all 7 (N1–N7) consented to participate. The study took place during a 17 month period from 2006 to 2008 and is part of a large investigation that also includes 12 TYAs and 19 significant others and explores their actions and experiences of network-focused nursing (Olsen and Harder, 2009; Olsen, 2009).

Recruitment commenced following approval from the Danish Data Protection Agency. A request to the Regional Research Ethics Committee proved that according to the Danish acts of scientific ethics the study, while not biomedical, could be undertaken without permission from the committee. Nurses, as well as the TYAs and significant others who were present in the youth unit during data generation, gave informed consent to observations of the nurses’ care giving during ordinary activities and special events like network meetings, and the nurses consented to talk about their experiences in planned interviews and informal conversations.

Data generation

Interviews with the nurses took place in a quiet room in the ward. Initially, five experienced nurses (>one year in youth unit) were interviewed, as they were judged to hold pivotal knowledge of the domain being studied. Analyses of data from these first interviews made the foundation for the following theoretical sampling where two less experienced nurses were interviewed. Subsequently, three of the seven nurses were interviewed again in relation to their involvement as primary care nurses for some of the participating TYAs. All interviews were performed by the first author, digital voice-recorded and transcribed verbatim into word-processing files.

Semi-structured questions guided the interviews starting with open-ended questions, e.g. “Tell me what it is like to work as a nurse focusing on the social network of the TYA and the parents?” and “Tell me about a situation with a specific TYA where you consciously aimed at strengthening the social relationships between the TYA and the significant others and/or family and friends”. These questions developed into more focused questions in later interviews following the principles of theoretical sampling to refine emerging theoretical ideas.

Non-participatory observations and informal conversations made it possible to study the phenomenon of network-focused nursing in action, to get a deeper understanding and to study meanings and processes at both a subjective and a social level (Charmaz, 2004). The first author frequently spent time during the 17 months of data generation observing care in the youth unit and having informal talks with the nurses. By turning up randomly or by appointment she was present at whatever was going on that particular day or she participated in planned events such as network meetings. Observations focused on actions, interactions, verbal and non-verbal communication and atmosphere, with the overall goal of making implicit meanings explicit. Field notes were written either during a session or immediately after, or observations and impressions were voice-recorded to be written later and subsequently transcribed to text in word-processing files for analyses.

Documents created by the staff of the youth unit were included as analyses proceeded and categories were developed. The documents show how the staff members express themselves about their care outside the context of the study and made it possible to explicate categories and optimise validity. These texts include a book (Hove et al., 2004) a DVD about the youth unit, a book chapter (Ravn et al., 2008) and information on the homepage of the department (www.onko.dk).

Data analysis

Data were analysed using the constant comparative method and principles of grounded theory (Glaser and Strauss, 1967; Charmaz, 2006). The initial coding was manually performed after transcription of each interview and observation. This coding was conducted line by line or segment by segment, sticking closely to data, remaining open to exploring theoretical possibilities and attempting to use gerunds (verbal nouns) in order to code with words that reflected the dynamic process of the participants and to the degree possible code data as actions. At this stage interpretive analyses started by looking for implicit assumptions and meanings. Data and codes were compared, first within each data set and then between sets of data, e.g. between interviews with the participating nurses. After initial coding the computer based analyses programme NVivo 7 was used to systematise the subsequent focused and theoretical coding processes towards generation of categories.

Theoretical memos were used to raise focused codes into conceptual categories and to construct abstractions. These categories were scrutinised for their power of representing meanings and actions, their purpose and for patterns of relationship (Charmaz, 2006). During this process hypotheses were developed, which guided the creation of new questions for further interviews and observations until categories were saturated.

Findings

The aim of supporting TYAs with cancer and their significant others to maintain, establish and strengthen their social network during the illness and treatment trajectory was not easily accomplished. We found that the main challenge for the involved nurses was to figure out new ways to help the young persons to continue

their normal growth and development during the treatment period. If one basic social process in dealing with this challenge should be explicated above others it could be expressed as *Creating a space* – that allowed the TYAs to preserve or establish an environment in which to develop in spite of the conditions invoked by disease and treatment. This basic social process reflects the overall goal of the nursing care explored and provides an interpretive frame of the actions and interactions that took place in nursing.

Bridging was found to be a core concept of the identified basic social process. Bridging and its implicit process of linking and moving across or over an obstacle embraces the main concern of the nurses in the youth unit and accounts for most of the variations in their pattern of behaviour. They tried to understand the values, norms and traditions of the TYA-world and the family-world by relating to and comparing with their own personal and professional values, norms and traditions. Bridging also accounts for processes of connection that the nurses tried to facilitate between the TYA, the family, other parts of the social network and life outside the hospital and illness context. Overall, bridging is an abstraction that comprises the nurses' constant attempts to meet and collaborate with the TYAs and the significant others in ways that would connect the seriously ill TYAs with their ordinary life.

The bridging processes were pushed forward by several interplaying nursing strategies described through four subcategories: *Tuning in*, *Framing the situation*, *Navigating towards the goal* and *Connecting people*. The strategies were influenced by conditions related to nurses', TYAs' and significant others' personality, resources, expectations and values, to family dynamics and traditions and the nature of their social network, to the seriousness of the cancer disease and to the general organisation of patient care services (see Fig. 1).

Tuning in

The nurses were first and foremost conscious about getting in tune with the TYA and the significant others. Through good rapport with them, the nurses aimed at creating confidentiality and open communication as the foundation for their care in general and for being invited into the more private world. Tuning in as a conceptual subcategory consists of three aspects, (i) Getting on the same wavelength, (ii) Embracing a different social convention, and (iii) Facing a broader spectrum.

Getting on the same wavelength refers to ways of reaching a mutual feeling of harmonious relationship with the TYAs. It was necessary to gain access to their perspectives and to enjoy their confidence. A youthful environment and atmosphere welcomed the TYAs in the youth unit, the communication style was directed to suit young people and the nurses made an effort to adapt to a youth culture. They explored the TYAs' relationships by asking direct questions about peers, best friends, leisure time activities and school. Humour and jokes were important and by sharing their everyday life, experiences and opinions the two parties gradually got to know each other and it paved the way for openness, “the club name was on her bag and that was actually what made a very good point of departure for our talk. While we filled in some papers and sorted out some practical things we talked a little about her sport and that I had done the same” (N6).

It was not always easy to reach a level of mutual understanding and openness. The nurses described how TV, computer and mobile phones would catch the TYAs' attention in a way that hampered the nurses' attempts, “I felt that they turned us down when they kept watching teli... we spent a lot of time trying to handle this rejection” (N1). The nurses had to accept not having eye contact and that “young people are able to multi-task and still remember what is said” (N4).

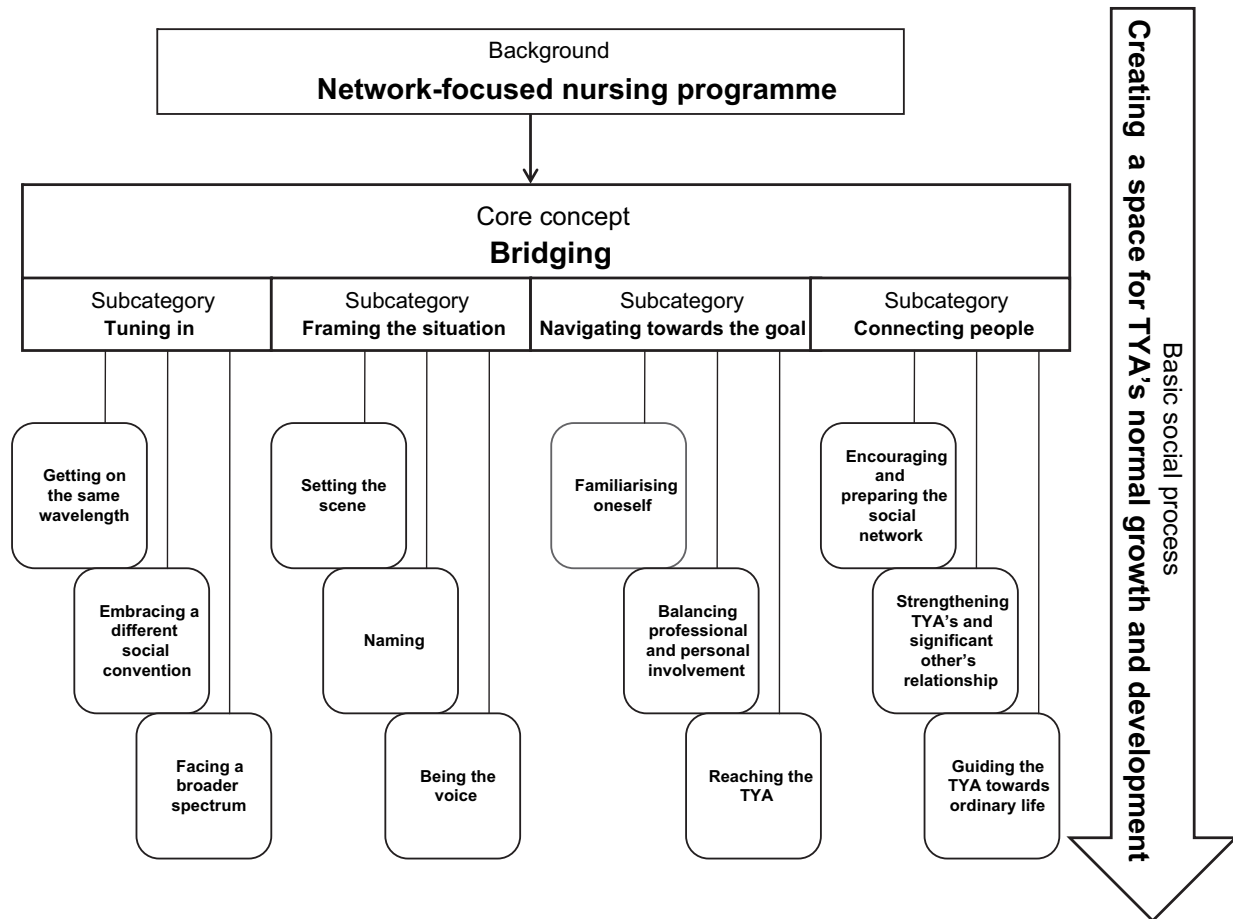


Fig. 1. Creating a space for TYA's normal growth and development (TYA: Teenage & Young Adults).

The young nurses, who were only about ten years older than the TYAs used this deliberately and approached the patients with a kind of “friend-talk” (N7). Older nurses told how they identified with the parents and therefore might be considered a “mother-figure” (N2), which in some cases could lead to closeness and in other cases, could create a barrier.

To get on good terms with the TYAs the nurses would sometimes “extend themselves as far as they could go” (N2), i.e. further than they would normally go when caring for adults. While hospitalised and disconnected from their friends TYAs used the nurses as “substitute friends” (N4) and more serious talks appeared to happen during evening or night shifts, “just before they fall asleep, when it is quiet, and we are alone, you can take the opportunity to sit down and chat and what starts with a chat often develops into a more intimate conversation” (N6).

Embracing a different social convention was a strategy repeatedly mentioned by the nurses who pondered over the differences between social conventions around adult patients and around TYAs. They experienced young patients as “less formal, free of norms and more relaxed” (N4). The nurses spent more time with them because they “ask for more” (N4), and they had to be precise and direct in their communication, e.g. if they wanted the TYAs to comply with appointments.

The presence of the significant others throughout the day intensified collaboration but also made the nurses feel that “the families are more demanding and you need to be more ready for change” (N6). The nurses experienced that they had to be careful to say and do the right things to preserve trust and they often felt “watched and checked” (N6), especially by parents.

Facing a broader spectrum was a challenging but necessary aspect of the nurses' care and they experienced having “at least two patients” (N7), “to some extent you are just as much nursing the parents as the young one... it does take a lot ... really a whole lot” (N6). The significant others being present in the youth unit most of the day lead to more questions and time spent on conversations, “you need to take them into account in your planning, when you plan your day ... that things often just take longer, because you have a mother or father or a close relative who needs attention” (N6).

The nurses needed to develop and use more competencies to carefully take into account the relationship between the TYA and the significant others, “I very quickly realised that the interplay between the young one, the parents and the nurse, is something quite different from when you have an adult patient in front of you” (N1). Nursing in the youth unit was complex and the nurses felt that aiming to involve the formal as well as the informal social network called for the kind of all encompassing care that they were taught during their nursing education, “where I've worked before it was all about curing the patients and then send them back home to whatever was there ... whereas here we know that it is extremely important that there are people there to support them” (N3).

Framing the situation

From the first encounter the nurses tried to be clear about the intentions behind their care and to be open about difficulties that might arise for the TYA and the family during treatment and hospitalisation. This conceptual subcategory includes three aspects, (i) Setting the scene, (ii) Naming, and (iii) Being the voice.

Setting the scene describes the way the nurses expressed their professional values and ideas. Through verbal introduction, leaflets, a DVD and via the homepage of the department, TYAs and their families were informed about the youth unit, the conditions and services offered, including the rationale behind. The nurses emphasised their respect for the young person's autonomy by using sentences like, "We will offer you a network meeting", "We will give you and the persons important to you information" and "You decide when you want visitors" (www.onko.dk). They made it clear that though significant others were welcome and expected to spend a considerable amount of time at the bedside, they also advocated that the TYAs spent some hours on their own, "We will encourage your parents to give you a couple of hours off during the day" and "We are also available if your parents want to talk to us about their situation and thoughts" (www.onko.dk). Another way of setting the scene was evident when the nurses arranged and chaired network meetings.

Naming covers how the nurses put words to taboos and problems that could be hard for the TYA and/or the family to bring forward. Especially, during network meetings that all followed the same agenda the nurses made sure that everybody attending the meeting heard the same information about the cancer disease, the treatment, adverse effects and prognosis. The nurses brought forward problems that might appear in everyday living and encouraged other family members and friends to provide support. They were observed to use expressions like, "P and his parents need your support ... it is hard to ask for help" and "you might feel dismissed if P rejects to go out with you ... hold on and keep calling him at other times ... it is normal to feel unsure about how to behave or what to say", and "though you want to support it can be difficult to hold on in the long run".

Setting the scene and naming were often interwoven, e.g. when a nurse discussed with a TYA what his "social network" was, whom he wanted to invite to the network meeting and whom to rely on in this situation. The nurse was then observed to draw on scenarios like, "you will get fed up with everything! Who would then be the person that you'd like to stand by you?" (N4).

Being the voice and thereby representing the TYA and the significant others was a strategy used by the nurses to bring important issues into the open. Before network meetings the nurses discussed with the TYA what issues to bring forward to the invited social network during the meeting and what to leave out. The nurses were aware that the TYAs would often remain rather quiet during these meetings and seemed relieved that somebody else gave voice to their concerns and legitimised their problems.

To avoid conflicts the nurses would also try to mediate, "the young one would say, 'I can't stand my mum sitting at my bed all the time ...' and when we passed on the message [to the mother] we often said, 'in our experience it is a good idea to ...'" (N1).

Navigating towards the goal

Targeting issues concerning the social network and the private sphere exceeded traditional nursing roles. Being invited in and getting involved could not be taken for granted. A few TYAs and parents declined the offers inherent in the nursing programme, e.g. a network meeting, and the nurses had to find other ways to support them. Further challenges that required careful navigation, were the risk of getting too personally involved in the family situation and difficulties in getting direct access to cooperate with the TYA, without the significant others intervening or acting as spokespersons for the TYA. This subcategory includes three aspects, (i) Familiarising oneself, (ii) Balancing professional and personal involvement, and (iii) Reaching the teenager and young adult.

Familiarising oneself with the family dynamics, traditions, roles and concerns of the significant others was important for the nurses. Through introduction to the unit and during the first weeks of careful observation the nurses would think of ways to reach mutual understanding and to establish trustful relationships, "so in that way I sort of feel my way and I always think that I have plenty of time. So eyes and ears in the beginning are very good" (N5) and "trust and confidence are key words from the very beginning, otherwise you don't get any further" (N3).

The nurses explored relationships and interactions between the TYA and the significant others and they tried to assess resources and strains in the wider social network. Especially parents' respect for their child's developmental level and autonomy was observed, "some parents really make room for their young ones ... and then there are others ... they take over immediately, you know, and I think you get a good impression of exactly that dimension" (N2). Getting to know and recognising family dynamics helped the nurses to allow for and secure the best possible support and conditions for the TYA.

Balancing professional and personal involvement was continuous and demanding. A long-term commitment, confidentiality and profound knowledge of the TYA and the family and their ups and downs created conditions for bonding. The primary care nurse often became an anchor, a trusted person that the TYA and the significant others turned to when overwhelmed by feelings or practical problems. This involvement could extend beyond the treatment period, like when a nurse after the death of a TYA kept in contact with the TYA's mother for several months trying to help her and the family to get on in life, "I simply couldn't let go ... the family had so much confidence in me ... I couldn't break ... they were in such pain" (N5).

Young nurses experienced that friendly communication with the TYA could confuse their perception of the nurse role. They felt that sometimes they moved in a "grey zone" and were in risk of behaving unprofessionally. Their individual considerations showed how they tried to balance between being a professional and being part of the more informal social network, "I'm most concerned about learning to set a limit. That I learn to tell the young ones what I stand for. That I'm not only some friend but that I'm also a nurse for them" (N7).

Reaching the teenager and young adult was not always easy. The nurses sometimes experienced the parents as barriers that they needed to overcome in order to reach the TYA. Wanting to do the best for their child and to be in control some parents overruled the TYA who then slipped into a passive role. Though parents would speak to their 16-year-old son as if he was still 12, the nurses kept speaking to the TYA in an age appropriate manner, "as long as we want to communicate with the young person, we need to start where they are" (N7). They kept trying to involve the TYAs and mobilise their own sense of responsibility, and to let them speak for themselves.

Recognising that the wellbeing of each member influenced the family unit, an important way to reach the TYA was to meet the needs of the parents or the partner. The TYA depended on strength and harmony in the family and expressed a relief that somebody took care of their worries and sorrow. In general, nurses spent much time talking, explaining and listening to the significant others as part of their care and during planned "parent-free time".

Connecting people

The nurses expressed awareness of their limited reach into the dynamics of the social network but were conscious of their health promoting possibilities. They used their professional position trying to unite people around the TYA and to support and

encourage TYAs' contact with friends and ordinary life. A means to facilitate this was offering to arrange network meetings. The subcategory includes three aspects, (i) Encouraging and preparing the social network, (ii), Strengthening teenager and young adult's and significant other's relationship, and (iii) Guiding the teenager and young adult towards ordinary life.

Encouraging and preparing the social network was a key strategy during network meetings. The nurses tried to find small practical but realistic everyday tasks that members of the social network could commit to do, making life easier for the TYA or the significant others. They suggested tasks such as cutting the lawn or cooking a meal and, "sometimes we suggest that their friends take turns to drive to the hospital, so at least once a week somebody will visit" (N2). When the nurses came in contact with the informal social network during visits in the youth unit or by phone they emphasised the importance of their support, e.g. by serving chips and drinks in the Youth Corner thus creating a light and cosy atmosphere in order to motivate the TYA's friends to come back for another visit.

The nurses facilitated conditions for connecting people and for overcoming any barriers. They provided contact between, e.g. the hospital and the community social worker, or between the hospital teacher and the school. Intending to pave the way for better understanding and continued contact the nurses on rare occasions would visit the TYA's class in order to demystify and inform about cancer and the TYA's situation.

Strengthening teenager and young adult's and significant other's relationship describes how the nurses tried to advocate that the TYA participated in ordinary youth-life and gave advice on how to take care of problems that could arise related to disease and treatment. Conflicts easily arose and parents asked nurses for advice, e.g. on how to communicate with their child, when and for how long it would be appropriate to visit and what position to take on the TYA's wish to join parties with friends and drink alcohol. Sometimes nurses acted as intermediaries in conflicts "... by putting words to how we see what happens between them" (Ravn et al., 2008). Supporting the supporters thus became an important part of the nurses' work. Parents and partners often expressed concern not to be good enough in their new roles and the nurses tried to empower the significant others through sparring, encouragement and acknowledging their thoughts and actions.

Guiding the teenager and young adult towards ordinary life by talking about everyday issues was a way to encourage the TYA to participate and make plans for the future. Feeling and looking different, being tired and not being able to do things as before would make TYAs inclined to cocoon and promote isolation. By asking questions about the TYA's life at home and how problems were handled the nurses gave attention to how the TYA managed at school and with friends. One of the nurses expressed a wish to improve this effort, "suddenly it is over and the young persons that I've met were really surprised ... and the effort of getting back to being young ... sometimes I wonder if we could do more to prepare them" (N6).

Discussion

In this study we investigated processes and strategies involved when oncology nurses in a specific youth unit focus on maintaining, establishing and strengthening a supportive social network for TYAs with cancer and their significant others. The study shows how a mental and social action of "Bridging" in various forms could help the nurses overcome barriers and pave the way for the care they aimed to deliver. Bridging as a core concept also delineates an abstract construction of connecting the young people with their social network and everyday world while threatened by isolation due to cancer and a long and burdensome treatment.

The nurses in the youth unit were caring for a non-traditional population of TYAs in an adult ward. The nurses also engaged in non-traditional nursing activities. These were decisive aspects of the nurses' bridging strategies. They were highly challenged to move from their experience and knowledge of caring for adults and engage in completely new ways of performing with the TYAs. When TYAs look like adults in size and stature, yet still reside with their parents or do not support themselves, they stand with one foot on the threshold of adulthood while the other foot remains in childhood. According to Gubrium who refers to Turner's theory of liminality (Turner, 1969) their identities are "betwixt-and-between" (Gubrium, 2009). This is also emphasised by society not having a name for this period in life (Arnett, 2000). Meeting a hospital system where you either have to fit in with children or adults elucidates TYAs' missing identities as young persons and as a category of patients in health-care. In the youth unit, however, the environment, the social conventions and the routines were tailored to recognise the identities and development of young people in transition.

Network-focused nursing fostered new nursing roles. It is widely recognised that nurses are usually in control of facilitation of partnership and patient participation (Henderson, 2003; Eldh et al., 2006; Sahlsten et al., 2008). This gate-keeping role changed in network-focused nursing and there was a shift of power from nurses to patients and significant others. If the nurse was to succeed in being invited into the more private world of the TYA and the family she had to earn her way. Abilities to tune in and to navigate appeared to be decisive to get an invitation to participate in TYAs' and their families' lives. Yet, the creation of trustful partnerships also included ability to balance involvement to avoid blurring of professional roles and friendship.

Our study shows how replacement of roles and power might improve the professionals' respect for the patients' autonomy. It was essential for the nurses that the package of support services presented was understandable and palatable to the TYA, the significant others and the wider social network. In the presentation of the nursing programme they proactively framed the situation by expressing their respect for the TYA's autonomy and the importance of involving the significant others and the wider social network. Studies on patient participation and partnership specifically point to the necessity of establishing this kind of foundation and outline the expectations and wishes of the parties (Coyne and Cowley, 2007).

The network meeting was an opportunity to demystify, normalise, and call people's attention to their obligation and possibility to provide support. Similar systematic efforts of protecting young people with cancer are seen in the Adolescent Resilience Model by Haase, who exemplifies how network meetings might specifically target enhancement of social support resources (Haase, 2004). More studies are needed that explore the social support outcomes of this kind of meetings and the experiences of the wider social network that attends them.

The study reveals the nurses' exceptional commitment and involvement with the young patients' significant others. In accordance with the aim of establishing a supportive social network the nurses targeted their attention to the significant others as key sources of social support. Parental support has been found to have a range of protective and buffering effects (Wills and Filer Fegan, 2001) and "being there" has been identified as a core concept in parenting a child with cancer, meaning "I'll be there for you" and "I'll never let you down" (Kars et al., 2008). "Being there" has been identified to encapsulate what is also important to young people with cancer. However, they also experience guilt with respect to their family members always having to be there for them (Woodgate, 2006) and psychological distress has been associated with conflicts between TYAs with cancer and their mother (Manne

and Miller, 1998). Professionals have been encouraged to assess and treat the system in which the youth interacts and exists (Brown et al., 2009) and to understand, recognise and manage the potential tensions at the earliest opportunity in the care setting (Grinyer, 2009). Nurses in this study were able to intervene in such situations by “being the voice”, putting words to their observations, and by spending time listening and supervising during sessions like “parent-free time”, thus recognising how hard it was to manage for all parties.

The purposeful navigation that the nurses performed was a key finding. Being convinced that they were responsible for trying to provide for a supportive social network, the nurses were persistent in their efforts to do so. Though strong advocates of network meetings, they acknowledged that a variety of ways could lead to the goal of creating a space for the TYA's normal growth and development. The role of nurses in social support of their patients has been emphasised by many authors. In keeping with the non-professional nature of social support Finfgeld-Connett advises nurses to encourage patients to use and enhance personal support networks (Finfgeld-Connett, 2005). Woodgate recommends that nurses give attention to how young people's significant relationships can be strengthened (Woodgate, 2006), and healthcare providers are advised to assist parents and other important adults and peers to understand the importance and type of support needed (Decker, 2007). This study shows that nurses are in a unique position to do so and that they take on the challenge to develop new ways of providing this kind of assistance.

Study limitations and strengths

The context of the study was one specific youth unit in a ward for adult patients and this holds some limitations. Firstly, it could be seen as a weakness that other youth units were not included to generate more data. However, we were not able to locate other youth units with a similar emphasis on network-focused nursing. However, the full participation of nurses who had experiences from the programme gives strength to the findings. Secondly, the local nature of the study means that caution needs to be exercised in making transferability claims. Nevertheless, we believe that the findings can be transferred to cultures and contexts where healthcare professionals acknowledge the potential of identifying a patient's social network and helping all parties towards the best possible process and outcome in the situation. Nurses can play a pivotal role to achieve this goal.

The validity of the study is supported by the use of many methods of data generation (Charmaz, 2004). We also chose to go back to the nurses in the youth unit to tell them about the findings before we brought closure to the analyses. The nurses recognised the relevance of the identified basic social process and the core concept of bridging.

Conclusions

The study gives a theoretical account of how nurses act and interact when wishing to support TYAs with cancer and mobilise resources in the patients' social network. Establishing a trusting and respectful partnership with an emerging independent young person and his or her family requires a highly sensitive approach, careful assessment and cooperation. Analyses lead to conceptualising a basic social process of “creating a space” for TYAs' normal growth and development and identified “bridging” as a core concept. The nurses of the youth unit that we studied proactively worked to preserve social integration of the patient and the significant others and to provide conditions for including the wider social network. The study contributes with a theoretical framework

for clinical practice by offering insight into new ways of caring for TYAs with cancer. Specialised care that embraces their lives and the close involvement of their significant others is a complex and highly demanding practice that needs to be addressed by nurses, educators, researchers and health policy makers.

Based on this study of network-focused nursing, we recommend that TYAs with cancer be cared for in specialised units, that nurses use their unique position to carefully consider and facilitate involvement of the patients' social network and that the care provided is described in the form of a theory based nursing programme, focusing on the young persons' developmental needs, youth culture and the need for high quality professional communication skills.

Authorship

Both authors have made substantial contributions to the study performed, the drafting and the final approval of the version of the manuscript submitted.

Conflict of interest

The authors have no financial and personal relationships with other people or organisations that could inappropriately influence (bias) this work.

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